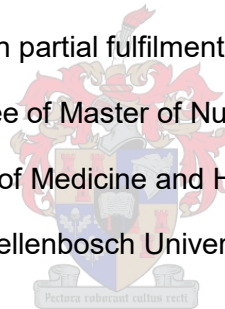


EXPLORING THE SELF-MANAGEMENT NEEDS OF ADOLESCENTS LIVING WITH HIV IN THE NELSON MANDELA BAY AREA OF THE EASTERN CAPE

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Thesis presented in partial fulfilment of the requirements
for the degree of Master of Nursing Science
in the Faculty of Medicine and Health Sciences
Stellenbosch University



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APRIL 2019

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Background: An increased number of human immunodeficiency virus (HIV) infected children are progressing to adolescence and beyond because of effective antiretroviral therapy (ART). Adolescents receiving ART tend to have poorer treatment outcomes compared to adults. HIV is now classified as a chronic illness and adolescents need the support of the whole family to self-manage (handle, direct and control) their chronic illness. When individuals and their families acquire self-management skills, they become responsible for the management of their chronic conditions, are able to control the illness and acquire healthy behaviours. Little is known about self-management amongst adolescents who live with HIV (ALHIV) and no self-management support programmes exist in the context of the Eastern Cape, South Africa.

Aim and objectives: This study aimed to explore the self-management needs of ALHIV in the Nelson Mandela Bay area of the Eastern Cape in order to make recommendations that can be used to develop a programme to support adolescents' HIV self-management. Specific objectives were to explore adolescents' beliefs, knowledge and understanding of their illness; describe their self-regulation skills and abilities and identify the resources adolescents utilise to facilitate them to manage their illness.

Methods: A qualitative descriptive design was applied. Thirteen adolescents between the ages of 14 and 19 years attending the West End and Booyesen Park clinics were purposely selected. The data were collected through individual interviews. Data analysis was done by using the six steps described by Creswell. Trustworthiness was enforced by adhering to the principles of credibility, confirmability, transferability and dependability.

Results: The research findings demonstrated that ALHIV, have limited knowledge and understanding about HIV and safe sex. Some ALHIV lack self-regulation skills and abilities such as taking their treatment, coping mechanisms, effective communication and disclosure of their HIV status to people outside the family. HIV services were not adolescent-friendly, with no dedicated services for adolescents and long queues. Support from family and friends plays a key role in the lives of the adolescents living with HIV.

Self-management programmes should include strategies to improve HIV and sexual health knowledge and self-regulation skills, particularly through using technology. Adolescent-friendly healthcare services and the involvement of parents and peers may be important to improve self-management support for ALHIV.

Conclusion: As an adolescent grow older, the responsibility of their care is transferred to them and they become more independent. The study revealed that ALHIV have several self-management needs; a programme that will support adolescents and their caregivers to acquire self-management skills may lead to better treatment and health outcomes.

Key words: Self-management; Adolescents; HIV

OPSOMMING

Agtergrond: As gevolg van effektiewe antiretrovirale terapie, is daar 'n toename in kinders met Menslike Immuungebreek virus (MIV), wat na adolessensie en verder vorder. Adolessente wat antiretrovirale terapie ontvang, is geneig om swakker behandelingsuitkomst in vergelyking met volwassenes te hê. MIV word nou geklassifiseer as 'n kroniese siekte en adolessente benodig die ondersteuning van die hele gesin om hul chroniese siekte te bestuur (hanteer, reguleer en beheer). Wanneer individue en hul gesinne selfbestuursvaardighede verkry, word hulle verantwoordelik vir die bestuur van hul chroniese toestande, hulle kan die siekte beheer en gesonde gedrag verwerf. Min is bekend oor selfbestuur onder adolessente wat met MIV leef (AMIVL) en geen selfbestuur ondersteunings programme bestaan in die konteks van die Oos-Kaap, Suid Afrika, nie.

Doelwit en doelstellings: Hierdie studie het ten doel gehad om die selfbestuursbehoefte van AMIVL in die Nelson Mandelabaai-gebied van die Oos-Kaap te ondersoek ten einde aanbevelings te maak wat gebruik kan word om 'n program te ontwikkel om adolessente se MIV-selfbestuur te ondersteun. Spesifieke doelwitte was om adolessente se oortuigings, kennis en begrip van hul siekte te ondersoek; hul selfregulerende vaardighede en vermoëns te beskryf en die hulpbronne wat adolessente gebruik om hulle te fasiliteer om hul siekte te bestuur, te identifiseer.

Metode: 'n Kwalitatiewe beskrywende ontwerp was toegepas. Dertien adolessente tussen die ouderdomme van 14 en 19 jaar wat die Westend en Booysepark klinieke bywoon, is doelbewus gekies. Die data is versamel deur individuele onderhoude. Data analise is gedoen deur gebruik te maak van die ses stappe beskryf deur Creswell. Betroubaarheid was afgedwing deur aan die beginsels van geloofwaardigheid, bevestigbaarheid, oordraagbaarheid en bestendigheid, te voldoen.

Resultate: Die navorsingsbevindinge het getoon dat AMIVL beperkte kennis en begrip oor MIV en veilige seks het. Sommige AMIVL het nie selfreguleringsvaardighede en vermoëns soos om hul behandeling te neem, hanteringsmeganismes, effektiewe kommunikasie en openbaarmaking van hul MIV-status aan mense buite die familie, gehad nie. MIV-dienste was nie adolessent-vriendelik nie, sonder toegewyde dienste vir adolessente en met lang rye. Ondersteuning van familie en vriende speel 'n sleutelrol in die lewens van die adolessente wat met MIV leef.

Selfbestuursprogramme moet strategieë om MIV en seksuele gesondheidskennis en selfreguleringsvaardighede te verbeter insluit, veral deur gebruik te maak van tegnologie. Adollessentvriendelike gesondheidsorgdienste en die betrokkenheid van ouers en eweknieë kan belangrik wees om ondersteuning vir selfbestuur vir AMIVL, te verbeter.

Slotsom: Soos 'n adolessent ouer word, word die verantwoordelikheid van hul sorg oorgedra aan hulle en word hulle meer onafhanklik. Die studie het getoon dat AMIVL verskeie selfbestuursbehoefte het en dat daar 'n behoefte is aan 'n program wat adolessente en hul versorgers sal ondersteun om selfbestuursvaardighede te bekom wat tot beter behandelings- en gesondheidsuitkomste kan lei.

Sleutelwoorde: Selfbestuur; adolessente; MIV

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ABBREVIATIONS

AFS	Adolescent Friendly Services
Aids	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ALHIV	Adolescents Living with HIV
HIV	Human Immunodeficiency Virus
PLHIV	People Living with HIV
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations Children Funds
WHO	World Health Organisation

CHAPTER 1

FOUNDATION OF THE STUDY

1.1 Introduction

An increased number of human immunodeficiency virus (HIV) infected children are progressing to adolescence and beyond because of effective antiretroviral therapy (ART). The global HIV paediatric epidemic is moving into a new phase because children on ART are aging into adolescence and maturing into adults (Sohn & Hazra, 2013:1). The World Health Organisation (WHO) defines adolescents as individuals in the 10-19 age group (WHO, 2009:14). The groups are divided into early adolescents who are between 10 and 14 years old and middle to late adolescents who are 15 to 19 years old (WHO, 2009:16).

Children whose life expectancy at one stage was two years are now living into their 20s and are having children of their own (Sohn & Hazra, 2013:16). Globally, the number of people living with HIV has increased due to the availability of and access to ART prolonging their lives (Swendeman, Ingram & Rotheram-Borus, 2009:1322). HIV is now considered to be a chronic condition and there is an increased focus on supporting patients with self-management. Self-management can be described as the interaction of health behaviours and related processes that patients and families engage in to care for a chronic condition (Modi, Pai, Hommel, Hood, Cortina, Hilliard, Guilfoyle, Gray & Drotar, 2011:475). It includes components such as knowledge and beliefs, self-regulation and social facilitation (Ryan and Sawin, 2009:219). When the individuals and their families acquire self-management skills, they become responsible for the management of their chronic condition, are able to control the illness and acquire healthy behaviours by purposefully engaging in the performance of learned behaviour (Ryan & Sawin, 2009:218).

Exploring how adolescents who live with HIV (ALHIV) manage their illness is a need that was identified by the researcher since it was observed that they generally have poor treatment outcomes and appear to cope ineffectively with their illness. The researcher is a Professional Nurse working in the primary health care services of Chatty clinic, which is in the Nelson Mandela Bay District, in the province of the Eastern Cape.

In Cape Town, a study that explored self-management amongst 13 to 18 year old ALHIV, identified several aspects of self-management adolescents needed support with. These were coping with disclosure and stigma, participating in healthcare decisions and in community activities, communicating about sensitive issues such as missing a dose of ART or sexual

behaviours, knowledge of their viral load and names of ARVs and remembering to take treatment (Crowley, 2017:269).

1.2 Rationale

A study that was done in clinics in Gauteng and Mpumalanga, South Africa, found that HIV-infected adolescents and young adults between 15 and 24 years receiving ART tended to be virologically unsuppressed, have high loss to follow-up rates and high virological failure rates compared to adults (Evans, Menezes, Mahomed, MacDonald, Untiedt, Levin, Jaffray, Bhana, Firnhaber & Maskew, 2013:900). There is therefore a need to support adolescents with self-management.

A study done by Millard, Elliot and Girdler (2013:104) found evidence that self-management programmes for people living with HIV/AIDS result in short-term improvements in knowledge, physical and psychosocial health and behavioural outcomes. It was found that targeted self-management interventions informed by thorough needs assessments, could provide beneficial outcomes for people living with HIV (Milliard, Elliot & Girdler, 2013:111).

There are 22 clinics that provide ART services to adolescents in Nelson Mandela Bay. The researcher conducted the research at the West End Clinic and the Booysen Park Clinic. West End Clinic and Booysen Park Clinic are situated in the Northern areas of the Nelson Mandela Bay District (NMBD) in the Eastern Cape. The clinics falls under the sub-district C area. The community at the West End Clinic is mostly Coloured and Afrikaans speaking. Parts of the area are affluent, but some areas in the community still experience poverty. The community at Booysen Park Clinic consist of Coloured and Afrikaans speaking and Black Xhosa speaking people. The area is experiencing severe poverty, drug abuse and gangs are prevalent in the area. Currently there is no programme in place to support adolescents with self-management at West End Clinic and Booysen Park Clinic.

The focus of this study was on older adolescents in the age group 14-19 years. Based on their cognitive developmental stage, they are more capable of self-management skills such as self-monitoring, planning, and goal-setting and evaluation (WHO, 2009:16). It is also the age at which parents tend to transfer responsibility. There are 30 adolescents in the age group 14-19 years that are on ART and attends the West End Clinic regularly for follow-up appointments and treatment. About a quarter of adolescents at this clinic do not attend the clinic regularly. If a patient has not attended the clinic for three months, they are considered to have defaulted. At least 35 percent of adolescents at the West End Clinic are not virally suppressed (District Health Information System (DHIS), 2017), meaning their viral load is not below 400 copies per ml (Department of Health HIV Clinical guidelines, 2015:79). Viral suppression is a distal

outcome of self-management and this indicates that they are not effectively managing their illness. Two adolescents died in 2016 (DHIS, 2017). The cause of death was Pulmonary Tuberculosis, an opportunistic infection that may have occurred due to the adolescents not being virally suppressed (Department of Health HIV Clinical guidelines, 2015:79). There are 35 adolescents in the age group 14-19 years that are on ART, and who attend Booysen Park Clinic regularly for follow-up appointments and treatment. About half of the adolescents at this clinic do not attend the clinic regularly. At least 20 percent of adolescents at Booysen Park clinic are not virally suppressed (DHIS, 2017).

The researcher, therefore, explored the self-management needs of adolescents in the context of the Eastern Cape in order to tailor a programme that will meet those needs and improve adolescent outcomes.

1.3 Problem statement

According to the District Health Information System (DHIS) there are 455 adolescents in the age group 14-19 currently on ART in the Nelson Mandela Bay District (DHIS, 2017). Adolescents that are on the ART programme attend the clinic monthly. It was noted by the researcher that adolescents experience problems managing their illness. It was estimated that about twenty percent of adolescents discontinued their treatment regime in 2016-2017 (DHIS, 2017). There is a paucity of literature about the self-management needs of adolescents living with HIV in a South-African context. Only one study, conducted in an urban setting in Cape Town, identified the components of adolescent HIV self-management (Crowley, 2017:279). Currently there is no programme in place to assist ALHIV with self-management. In order to develop a programme that will meet their needs and is contextually appropriate, the researcher first needed to explore their needs.

1.4 Research question

What are the self-management needs of adolescents who live with HIV in the Nelson Mandela Bay area of the Eastern Cape?

1.5 Research aim

The aim of the research is to explore the self-management needs of adolescents who live with HIV in the Nelson Mandela Bay area of the Eastern Cape in order to make recommendations that can be used to develop a programme to support adolescents' HIV self-management.

1.6 Research objectives

The objectives are to:

- Explore adolescents' beliefs, knowledge and understanding of their illness.
- Describe the self-regulation skills and abilities of adolescents.
- Identify the resources adolescents utilise to facilitate them to manage their illness.

1.7 Conceptual framework

The Individual and Family Self-management theory (IFSMT) is a relatively new theory that describes self-management in the context of the family and the individual, taking into account the physical and social environment and the characteristics that is unique to the family members. The processes of self-management can be broken down in components, namely; facilitation of knowledge and beliefs, enhancement of self-regulation skills and abilities, and social facilitation. Self-management is normally centred on the individual but with IFSMT, it expands to the family. According to the family system, a change in one family member affects the whole family (Ryan & Sawin, 2009:222).

Ryan and Sawin (2009:218) identified several self-management processes and theorised that self-management processes are responsible for self-management behaviours, which in turn affect outcomes such as health-related quality of life and viral suppression. Crowley (2017:279) identified five components of self-management in a South African context, which are based on the IFSMT, namely; Believing and Knowing; Goals and Facilitation; Coping and Self-regulation; HIV Biomedical Management and Participation.

1.7.1 Believing and knowing

Believing and knowing concerns views and ideas about one's illness, the future and confidence to self-manage (Ryan & Sawin, 2010:124). It includes comprehension of how to navigate the healthcare system and the importance of treatment (ART) (Crowley, 2017:280). Knowledge in itself does not lead to behaviour change, but the enhancement of knowledge or specific health beliefs may lead to behavioural change. Knowing about their illness, like what happens when they do not take their treatment every day, may lead to adherence to ART and viral suppression (Figure 1.1).

1.7.2 Goals and facilitation

Goals and facilitation are described as internal and external motivation for self-management in the form of setting individual goals and support by family, healthcare workers, peers and friends to take care of one's health (Crowley, 2017:280). Social facilitation is inter-related with knowledge and beliefs and self-regulation. Knowledgeable engagement of adolescents in supported self-regulated behaviour may lead to viral suppression and increase their health related quality of life (Ryan & Sawin, 2009:124).

1.7.3 Participation

Participation is described as being actively involved in one's healthcare and in the community and includes communication with healthcare providers, participating in decisions, asking questions and participating in the community (Crowley, 2017:2280). The ALHIV become more involved in the management of their illness, they participate in decision making and therefore take ownership of their illness. Participation can also be viewed as a self-management behaviour (Ryan & Sawin, 2009:125). Active participation may lead to improved clinical outcomes and health related quality of life.

1.7.4 HIV biomedical management

HIV biomedical management includes knowledge of and motivation to understand whether one is doing well on treatment or not (Crowley, 2017:2280). Barnes, Abramowitz, Lagrange, Chandwani, Moschel and Koenig (2013:323) found that few adolescents knew their viral load or CD4 count and that discussions with the healthcare provider about CD4 and viral load were associated with higher HIV knowledge.

1.7.5 Coping and self-regulation

Coping and self-regulation are skills that are related to managing the HIV stigma, making decisions about disclosure and integrating taking treatment into one's daily routine (Crowley, 2017:280). The adolescent that develops self-regulation skills and experiences positive influences, may engage in preventative health behaviours (Ryan & Sawin, 2009:125). Engagement in self-regulation behaviours enhances self-efficacy and leads to engagement in self-management behaviour. Goal-setting, self-monitoring and reflective thinking, decision-making, planning and action, self-evaluation and management of physical, emotional and cognitive responses are associated with health behaviour change. This enhances a person's ability to manage a chronic illness or risk behaviours (Ryan & Sawin, 2009:220).

The identified needs of adolescents, based on these self-management processes, may be used to tailor a self-management support programme that meets these needs (Figure 1.1)



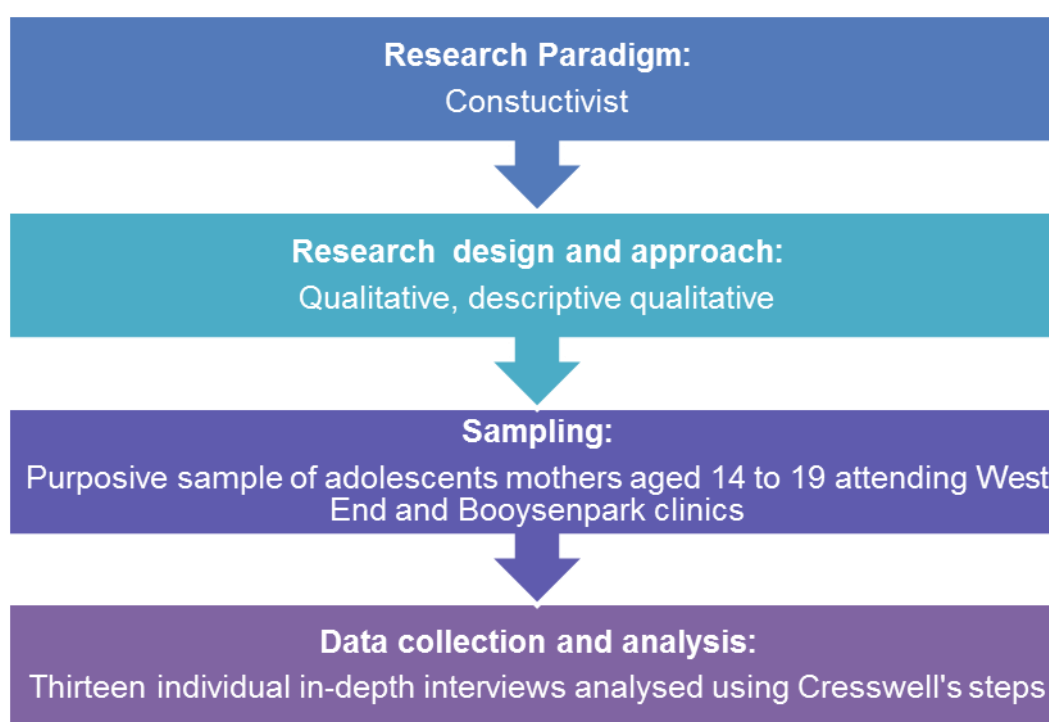
Figure 1.1: Conceptual framework for the study

(adapted from Ryan & Sawin, 2009; Crowley, 2017)

1.8 Research methodology

The research methodology involves processes such as the selection of a topic, stating the problem and justifying the significance of the study. This is followed by designing the study, identifying sources of data, such as subjects and gaining access to those sources of data. Subjects are recruited, data gathered, described, analysed, and interpreted. Finally, a written report of the results is developed (Burns & Grove, 2011:83).

Figure 1.2 provides a brief overview of the research methodology of the study that will be discussed in detail in chapter 3.

**Figure 1.2: Overview of the research methodology used**

1.8.1 Research design

The experiences of the ALHIV were explored by the researcher by using a qualitative research design. The researcher used descriptive research, with the purpose to describe the experiences of the study participants (Burns & Grove, 2011:76).

1.8.2 Study setting

The study was conducted at two primary health care clinics in the Nelson Mandela Bay District; namely West End Clinic and Booyesen Park Clinic.

1.8.3 Population and sampling

According to the DHIS there were 455 adolescents in the age group 14-19 on ART in the Nelson Mandela Bay District in 2016/2017. At the time of the study, 30 HIV-infected adolescents of this age group attended West End Clinic and 35 HIV-infected adolescents attended Booysen Park Clinic respectively, according to the DHIS (2017). Purposive sampling was used to sample 13 adolescents.

1.8.4 Data collection tool

To collect the data, interviews were conducted. The interviews were conducted individually with no parent or caregiver present, because the adolescent may not be open to sharing and the caregiver may be tempted to interrupt. Interviews were conducted in private and at a place and time selected by the participant. An interview guide was used, see appendix 6. The interviews were recorded on an audio-recorder.

1.8.5 Pilot interview

A pilot study is a smaller study that is conducted in advance of a proposed study and it allows researchers to test aspects of the study design (Burns & Grove, 2011:49). The researcher conducted one interview with an HIV-infected adolescent.

1.8.6 Trustworthiness

Polit and Beck (2014:323) use four criteria to describe the trustworthiness and evaluate the quality of research, namely, credibility, confirmability, transferability, dependability and authenticity. These criteria will be discussed in detail in chapter three.

1.8.7 Data collection

The researcher asked the healthcare workers working in the ART clinics, to refer patients, since a person's HIV status is a sensitive issue. The adolescents were recruited at the clinic and then appointments were scheduled, and contact details were obtained. Interviews were conducted with the adolescents.

1.8.8 Data analysis

The steps suggested by Creswell were used to analyse the data (Creswell, 2014:196).

1.9 Ethical considerations

Ethics approval was obtained from Health Research Ethics at the University of Stellenbosch, reference number#: S18/01/004. Permission was obtained from the Eastern Cape Department of Health, reference number, EC_201803_013. Permission to conduct research in the Nelson Mandela Metro District was also obtained.

The study complied with the ethical principles of the Declaration of Helsinki that was released in 1964 by the World Medical Association (WMA) (Burns & Grove, 2011:105) and updated in 2013 (WMA, 2013). During qualitative research the researcher wants to hear the voice of the participants and to achieve this, a trust relationship with the participants has to be established.

During recruitment of participants, gatekeepers such as caregivers was used, to ensure that no coercion of participants that was involved in the study occurred. No participant was forced to be involved in the study. The researcher also ensured that the gatekeeper did not coerced the participants to take part in the study. This may have not been done through force, but through the social expectation of the gatekeeper (Hennik, Hutter & Bailey, 2011:66). In case of orphans participating, the legal guardian gave consent. A further ethical issue with participant recruitment was that individuals wished to participate in the study but others did not want them to participate. In this case, a caregiver did not want people outside the immediate family to know that the adolescent is HIV-infected (Hennik et al., 2011:67). The researcher tried to encourage the caregiver to allow the adolescent to participate in the study by providing them with all the information about the study and the research objectives. If the caregiver still refused for the adolescent to participate in the study, the researcher decided not to pursue the issue to prevent the adolescent from having serious problems with the caregiver (Hennik et al., 2011:67).

The researcher provided the participants with enough information about the study and the procedures to follow during the interview or discussion stage and explained to the participants that the interview will be recorded and obtained consent (Hennik et al., 2011:69). The researcher maintained anonymity and confidentiality during data collection. This was achieved by incorporating the ethical principles of autonomy, beneficence, non-maleficence and justice.

Autonomy: The participants had the free choice to make their own decision to participate in the study. Enough information was provided to them to make an informed choice. The consent form was available in the home language of the participant. The participant was not forced by the researcher, guardian or caregiver of the participant to participate in the study.

Beneficence: The ethical principle of doing well to others and promoting well-being being, was observed. The researcher ensured that no harm came to the participants. The interviews was conducted during the day, to avoid the participants walking at night. It was anticipated that when problems emerge from the interview, such as the participant becoming distressed, the participant would be referred to counsellors. However, this was not necessary. Further, the participants did not incur any costs by participating and their travel costs were reimbursed.

Non-maleficence: The ethical principle of avoiding harm. To ensure complete confidentiality the researcher restricted who listened to the recording of the interviews, so that only members of the research team had access to the recordings (Hennik et al., 2011:72). The researcher ensured that accidental disclosure did not happen, by conducting interviews privately. The researcher needed to legally report any child abuse if identified, but that was not necessary.

Justice: To treat the participant fairly. The researcher made written transcripts from the recorded interviews. The researcher ensured that the transcripts were anonymous by removing any information that may identify a participant. The researcher ensured that fair selection occurred by using the study inclusion criteria to select participants (Hennik et al., 2011:72).

1.10 Definition of care terms

Adolescence: Adolescents are individuals in the 10-19 years age group. Adolescents used in the study are from the age group 14-19 years. Based on their cognitive developmental stage, they are more capable of self-management skills such as self-monitoring, planning, and goal-setting and evaluation (WHO, 2009:16).

Self-management: To care for a chronic condition, patients and families engage in interaction of health behaviours and related processes that are described as self-management (Modi et al., 2011:475). Self-management includes the following components, social facilitation, knowledge and beliefs, and self-regulation skills and abilities (Ryan & Sawin, 2009:219).

Adolescent-friendly health services (AFHS): These aim to ensure that existing health services are able to respond effectively to the specific needs of adolescents, given the reality of the available health resources and infrastructure (WHO, 2009:34).

HIV-infection: HIV is a virus that attacks the immune system, the body's natural defence system. Human beings infected with the virus are referred to as HIV-positive. Both the virus and the infection it causes are called HIV (UNAIDS, 2011:15).

1.11 Duration of the study

Ethics approval was obtained from Health Research Ethics at the University of Stellenbosch on 5 March 2018, and permission was obtained from Eastern Cape Department of Health on 27 March 2018. Permission to conduct research in the Nelson Mandela Metro District was obtained on 13 April 2018. Data collection was done between April and May 2018. Data analysis was done between August and October 2018. The thesis was handed in for examination in December 2018.

1.12 Chapter outline

Chapter 1: Foundation of the study

The foundation of the study introduces the study topic, aim and objectives and gives a brief overview of the methodology.

Chapter 2: Literature review

The literature review related to the self-management needs of ALHIV is described in this chapter.

Chapter 3: Research methodology

An in-depth description of the research methodology applied in the study is provided and includes the design, population and data analysis.

Chapter 4: Findings

The findings are presented and interpreted based on the data that were collected during the study.

Chapter 5: Discussion, conclusions and recommendations

The findings are discussed based on the study objectives. Conclusions and recommendations are made based on the scientific evidence obtained from the study.

1.13 Significance of the study

The study assisted in identifying adolescents' self-management needs in order to develop a programme that will meet their needs. Further, supporting them to develop the necessary skills to cope with a chronic illness may improve adolescent outcomes in line with global goals.

1.14 Summary

The researcher used a qualitative study to explore the needs of adolescents related to the self-management of their illness. A qualitative descriptive approach was used in order to describe the experiences of the participants as they are lived. As part of data collection in a qualitative approach, the researcher made use of interviews, and open-ended questions were asked, to allow the researcher to gather sufficient data. The thesis was submitted in December 2018. The literature review is discussed in the next chapter.

1.15 Conclusion

Being an adolescent and being HIV-infected comes with many challenges. ALHIV need to be assisted in self-managing their illness. Adolescent friendly programmes have to be designed to assist the adolescent to make informed decisions about their illness. The adolescent has to

learn self-management skills and need assistance to plan their lives and future to become productive, healthy and self-reliant citizens. Knowledge of their self-management needs may allow for tailoring a programme that meets their unique needs which may in turn improve health outcomes.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

Adolescence is a highly volatile stage in the life of a young person. As adolescents are currently being left behind in the progress made in the HIV pandemic, they need to be involved in finding solutions for changing adolescents' behaviour and attitudes that underlines the disease (WHO, 2009:25). More than 19 percent of adults (ages 15-49) in South Africa are living with HIV. The HIV burden varies widely by geography, age and gender and for key and vulnerable populations. Although new HIV infections declined from 360 000 in 2012 to 270 000 in 2016, adolescent girls and young women as well as other key and vulnerable populations remain most heavily affected by the epidemic. South Africa has the world's largest HIV treatment programme, with 3.7 million people initiated on antiretroviral therapy as of December 2016 (Department of Health, 2017:13).

In 2014, the WHO published a document called *Health for the world's adolescents: A second chance in the second decade*. This document stated that HIV was the biggest killer of adolescents in the 10 years prior to the publication, second only to road traffic accidents. Although global HIV rates are declining because of effective prevention of mother-to-child transmission, these findings clearly showed that adolescents living with HIV (ALHIV) had been overlooked (UNICEF, 2016:10).

The focus of this literature review is to summarise the scientific evidence related to the self-management needs of HIV-positive adolescents. There is a plethora of literature focusing on adolescents, people living with HIV (PHIV), adherence and risky behaviours of adolescents. This literature review is delimited to information that provided a background to the study, the elements of and self-management needs of HIV-positive adolescents. The purpose of a literature review in qualitative research is for the researcher to acquire an understanding about the research topic (Hart, 2018:192). A preliminary review was done before data collection and the review was completed after data collection.

2.2 Electing and reviewing the literature

Essentially a literature review generates a picture of what is known and not known about the research problem (Brink, van der Walt & van Rensburg, 2012:54). For this study, the following databases were searched: PubMed, MEDLINE and Google Scholar. The key words that were used to conduct the literature were: HIV infected adolescents, self-manage, peer pressure,

psychological effects of adolescence, and adolescent behaviour. The majority of articles were published between 2009 and 2018. Two hundred and nine articles were screened. Grey literature included the following: South African National Guidelines, Joint United Nations Programme on HIV and AIDS (UNAIDS) statistics, District Health Information System (DHIS) statistics, the Integrated Management of Adolescent and Adult Illness (IMAI), Statistics South Africa, HIV Clinicians Society guidelines on antiretroviral therapy in adolescents and young adults, the United Nations Children's Fund (UNICEF) statistics and the National Adolescent and Youth Health Policy.

This literature review is structured under the following headings: epidemiology of HIV-infected adolescents; policies and fast tracking strategies; adolescent development; adolescent self-management needs; and Interventions to improve self-management.

2.3 Epidemiology of HIV-infected adolescents

Globally about 2.1 million adolescents aged 10–19 years were living with HIV in 2016. That is a 30 percent increase from 2005. Trends in new HIV infections among older adolescents (aged 15–19 years), between 2010 and 2016, ranged from a 27 percent increase in Eastern Europe and Central Asia to a 21 percent decline in Eastern and Southern Africa (UNICEF, 2017:3). In 2015, it was estimated that adolescents represented the fastest growing age group of people living with HIV (PLHIV), and that they accounted for 5.9 percent of the burden of HIV (UNICEF, 2017:7). The estimated number of adolescents in the age group 15-19 years that were newly infected with HIV around the world in 2015 was 250 000 (UNICEF, 2017:34). Two out of three new infections among adolescents age 15 -19 years occurred in sub-Saharan Africa. Out of a total of 250 000 new infections globally, the number in Eastern and Southern Africa was 130 000, representing 53 percent of the global number (UNICEF, 2017:34).

Estimations indicate that South Africa, in 2017, had 7.06 million people living with HIV in the age group 15-49 years old. The age group 15 to 24 years represented 7.06 percent of the population of people living with HIV in South Africa (Stats SA, 2017:8). It is estimated that the number of new infections among adolescents aged 15-19 in 2015 in South Africa, was 59 000 (UNICEF, 2017:74). There were 240 000 children in the age group 0-14 years living with HIV in South Africa, that is 13 percent of the total number of people living with HIV in South Africa (UNICEF, 2017:24). With the availability of antiretroviral treatment, most of these children will be transitioning into adolescence.

In the Eastern Cape, there were 28 242 HIV-positive children in the age group of 0-14 years, which represents 2.3 percent of PLHIV in the Eastern Cape. The age group 15-24 represent 7.25 percent of PLHIV in the Eastern Cape (South African Health Review, 2017:72). It was

also estimated that in the Eastern Cape, the HIV prevalence rate is 10.1 percent in the age group 15 years and over (DHIS, 2018)

New infections in the Nelson Mandela Bay Municipality (NMBM) were at 2400 in the age group 15 years and over (DHIS, 2018). Also in the NMBM, the HIV prevalence rate was 8 percent in the age group 15 years and over (DHIS, 2018). From the above mentioned statistics it can be seen that there are many HIV-positive adolescents that become newly infected in adolescence and that children on ART will be transitioning into adolescence requiring adolescent-specific health care services.

2.4 Policies and fast tracking strategies focused on improving the outcomes of adolescents living with HIV

UNAIDS launched a strategy to fast track and reach people being left behind by the Millennium Developmental Goals. This is a call to reach the 90-90-90, treatment targets by 2020 (UNAIDS, 2016:58). These targets are to ensure that 90 percent of people (children, adolescents and adults) know their HIV status that 90 percent of people knowing their status are receiving treatment and that 90 percent of people on treatment have suppressed viral loads.

Several global and national strategies have been employed to enact these goals. Some of these strategies will now be briefly discussed.

2.4.1 Global strategies: all in to end the adolescent Aids epidemic

The global consultation group of UNAIDS considered the populations that were left behind and identified challenges and gaps in the response to HIV infection. The data were collected according to regions (UNAIDS, 2016:58). UNICEF and UNAIDS launched the ALL IN response to galvanise global action towards HIV prevention and promotion of treatment access amongst adolescents.

The priority populations identified in the ALL IN framework are the age groups 10-14 years and 15-19 years. This includes all adolescents living with HIV and includes adolescents who acquire HIV during adolescence and adolescents with vertically-acquired HIV (diagnosed and undiagnosed). Adolescents in risk populations are also a priority; for example, adolescent girls (particularly in sub-Saharan Africa) and adolescents in key population groups such as adolescents who inject drugs, who are gay, bisexual, transgender and adolescents who sell sex (UNAIDS, 2016:3).

The Sustainable Development Goals that were identified by the UNAIDS and will be prioritised are Good health and well-being (goal 3); Gender equality and reduction in inequality (goal 5);

Peace, justice and strong institutions (goal 16); and Partnership for the goals (goal 17) (UNAIDS, 2016:9). With regard to the goal for good health and well-being, it is recommended that children and adolescents living with HIV access testing, that they must know their status and must be immediately offered and placed on treatment. Young people, especially young women and adolescent girls should be empowered to protect themselves from HIV, they should also be able to access services where they will find everything at one service point. This includes youth-friendly HIV services, sexual and reproductive health services, reduction of harm information and services that can be accessed independently and equally by young women and men (UNAIDS, 2016:10).

2.4.2 National strategies to manage HIV in adolescents: a South African approach

Nationally, there have also been several strategies introduced that focus specifically on adolescents. It is acknowledged that many strategies are focused on prevention, but strategies that are focusing on supporting adolescents who live with HIV will be discussed.

2.4.2.1 National adolescent and youth health policy

The Adolescent and Youth Health Policy (AYHP) of 2017 aims to promote the health and well-being of young people. To achieve this, the policy addresses the use of youth orientation programmes and technologies. The youth use mobile phones and the internet now more than before, and this method may be used to reach adolescents about health matters (Republic of South Africa, 2017:14). The policy promotes the use of health information applications, health monitoring tools and feedback mechanisms. Young people should be able to access comprehensive health services, where prevention, testing and treating of HIV, tuberculosis and non-communicable diseases are addressed. The young person should be able to access all health programmes at one point, with no need to be referred to another facility. The operating hours of the facility need to accommodate learners and students to be able to access the facility after school. Male medical circumcisions and other relevant procedures must also be done during school holidays, to avoid the youth being absent from school. The policy also aims to promote healthy nutrition that will lead to a reduction in obesity. There is a move towards engaging the youth in policies and programmes so that they can provide input and be responsible for their own health and wellbeing (Republic of South Africa, 2017:14). Youth representatives on clinic committees could assist in ensuring that youth needs are met. This means that adolescents accessing ART should be able to receive information, access services at convenient times and be involved in programmes.

2.4.2.2 She conquers campaign

She conquers is a national campaign aimed to protect and promote the rights of adolescent girls and young women across South Africa. The campaign was introduced in 2016 as a three-

year plan to focus on young woman and adolescent girls. The first phase has been implemented in the 22 districts with the highest HIV burden. She conquers aims to decrease teen pregnancies and to keep girls in school until matric. To decrease sexual and gender-based violence and to increase economic opportunities for young people. HIV positive adolescents need to practice safe sex to avoid pregnancy and prevent infecting their partners or babies. The HIV positive adolescent also needs to know and understand that they can be economically independent, by working or attending university or college (RSA She conquers, 2017:1).

2.4.2.3 South African National Strategic Plan on HIV, TB and STIs 2017-2022

The South African National Strategic Plan on HIV, TB and STIs 2017- 2022 (NSP) serves as a roadmap for the next stage of the South African journey towards a future where these three diseases are no longer public health problems (Department of Health, 2017:3). All HIV-positive adolescents have to be on ART and their viral load has to be suppressed. A priority is to get the HIV-positive adolescents that are defaulting or lost to follow up back into the system (Department of Health, 2017:10).

The NSP recommends interventions to reduce risky behaviour amongst the youth through programmes that target the individuals, parents and families. Age-specific support should be provided for learners and out of school youth. Economic opportunities for targeted groups of young people should be increased. By doing this, the youth will be economically independent and will be able to look after themselves. The provision of rehabilitation services, psychosocial support services and mental health services for people living with HIV and TB should be increased and easily accessible for the youth (Department of Health, 2017:21).

Community support groups are another method that could be utilized to deal with internalized stigma of people living with HIV and TB and this could include peer support groups for the youth. Differentiated care is one of the strategies that can be used to ensure that adolescents engage in care and remain in care. Differentiated care for HIV requires delivery of different care packages for people based on their needs. This includes the type of service delivered, the location of service delivery, the provider of the services and the frequency of the services (WHO, 2015:1). For HIV-positive adolescents this can mean adolescent friendly services, where all their needs are met.

2.5 Adolescent development

Adolescence is a period of transition marked by developments such as sexual identity formation and social and cognitive maturation. Negotiating these milestones can be both rewarding and challenging for all adolescents; but for adolescents living with HIV (ALHIV), this

transition is made difficult by a chronic, often stigmatized and sexually transmitted disease (Mark, Armstrong, Andrade, Penazzato, Hatane, Taing, Runciman & Ferguson, 2017:25).

Adolescence is also a stage of rapid development which includes neurological, cognitive, psychological, social and sexual development (WHO, 2009:16). This is a stage where peer relationships become increasingly important. The areas of adolescent development are categorised in seven categories. These are: growth of the body, growth of the brain, cognition, psychological and social family, peer group and sexuality (WHO, 2009:16).

Adolescents more often find themselves in difficult situations because of their risky behaviour, such as becoming involved in criminal activities (Alperen, Brummel, Tassiopoulos, Mellins, Kacanek, Smith, Seage & Moscicki, 2014:7). Adolescents also exhibit increased risk-taking behaviour when observed by their peers. For HIV-positive adolescents, this risky behaviour may lead to the transmission of HIV to partners that are unaware of the status of the adolescent, leading to an increase in new infections (Alperen et al., 2015:7). During the adolescence period, relationships move away from the family and expand to a wider network of peers. The adolescents experience changes in social expectations and they need a higher level of thinking (WHO, 2009:15). HIV-positive adolescents have to work through the complex demands of treatment, social pressures, and their vulnerable health, also dealing with bereavement and disrupted care, without having necessarily developed the skills to manage these circumstances (Bernays, Jarrett, Kranzer & Ferran, 2014:1356). Therefore, adolescents need to be taught self-management skills and adolescence may be an opportune time for it to happen.

2.6 Adolescent self-management needs

Self-management concerns handling, leading and taking control of one's illness (Sawin, 2017:169). The components of self-management was described in chapter 1, and broadly concerns illness, individual and environmental factors; processes such as knowledge, beliefs, self-regulation and social facilitation; and outcomes such as health behaviours and health status (Sawin, 2017:170). In order to encourage the ALHIV to self-manage their illness, they have to be taught skills like self-monitoring, planning, and goal-setting and evaluation (WHO, 2009:16). Self-management education complements traditional patient education in supporting people to live the best possible quality of life with their chronic condition.

Several self-management needs of adolescents have been identified in the literature. Most studies have been conducted about adherence, but several challenges are similar and these are summarised below.

2.6.1 Knowledge about HIV and safe sex

Adolescents do well when they are equipped to understand their illness. As HIV-positive children mature, services have to be available to counsel the adolescent on safe sex and ART adherence (Evans, et al., 2013:1). Knowledge of what HIV is and that it is controlled by taking treatment, encourages patients to take their treatment (Ankrah, Koster, Mantel-Teeuwisse, Arkinful, Agyepong & Lartey, 2016:331). A study that was done in Cuba about ART adherence in children and adolescents found that when the children, adolescents and caregivers have insight into ART adherence and knowledge about HIV, it leads to high levels of treatment adherence (Castro, Gonzalez & Perez, 2015:39). As their knowledge about HIV increases, contraception use among adolescent females increase and this may lead to female empowerment and enhanced educational and economic opportunities for adolescents (Hagey, Akama, Ayieko, Bukusi, Cohen & Patel, 2015:20124). Healthcare workers have to incorporate discussions about sex in the context of adolescents' relationships and explore issues of empowerment (UNICEF, 2016:30).

2.6.2 Assistance with communication and disclosure

According to WHO, children of school-going age should be told of their HIV-positive status, and younger children should be informed slowly to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure (WHO, 2015:28). In many cases adolescents are not informed about their HIV status and talking to them about their HIV status seems to be a particularly complex, emotion-laden and difficult task for both caregivers and healthcare providers (Watermeyer, 2013:597). Some children enter adolescence without knowing about their HIV status. This may have significant implications for their health, treatment, emotional well-being, adherence and the prevention of the spread of HIV. Clinicians and researchers need to work together to find ways of enhancing disclosure practises. They need to clarify existing confusion and uncertainty around roles and responsibilities with disclosure. Supporting staff and caregivers must ensure that disclosure happens in an appropriately sensitive and timely manner with children (Watermeyer, 2013:595). Adolescents may be emotionally unprepared for disclosure because of their fear of the stigma attached. Sometimes caregivers lack the skills or knowledge to facilitate disclosure (Watermeyer, 2013:593). Moreover, adolescents are entering a period where they will have relationships and therefore the issues around disclosure are also related to disclosing their status to partners.

Adolescents need to be taught practical strategies to manage the potential stigma and disclosure so that they can learn what it means to grow up with HIV, what their responsibilities are, and the skills to manage the social consequences of living with HIV (Bernays et al.,

2014:1357). Adolescents want to be told the truth about their HIV status and illness, but they may have preferences about how they want this to be done. In a study that was done in Zimbabwe on HIV disclosure of perinatally-infected adolescents, it was found that many adolescents want to be told about their HIV status in a healthcare setting by a doctor, nurse or counsellor. They feel that the presence of a healthcare worker makes the illness more real (Kidia, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand, 2014:4).

2.6.3 Taking treatment

Healthcare workers expect adherence from adolescents, but adolescents face great social barriers in maintaining adherence. What happens outside the clinic affects the ability of adolescents to adhere to the clinician's guidance and expectations (Bernays et al., 2014:1355). The stigma that still prevails in the communities about HIV forces the adolescents to take their treatment in secret. They have to take treatment every day of their lives and this is made more challenging by poverty. For example, they might be living in a house that is crowded where there is little to no privacy and access to food (Bernays et al., 2014:1355). A study that was done in Ghana about facilitators and barriers to antiretroviral therapy adherence among adolescents, found that most of the adolescents reported forgetfulness as a barrier to adherence and non-compliance to medication. It was also found that social activities had a strong effect on the ability of adolescents to remember their treatment times. Reminders were used to overcome this issue, like the use of an alarm on a mobile phone (Ankrah et al., 2016:333). Adolescents may not always take their treatment at home, because they may be involved in public activities that may overlap with their treatment times. They may want to keep their ART treatment away from peers, therefore a special plan has to be worked out for these adolescents, for example, to give them tablets instead of solutions (Ankrah et al., 2016:334). In a study done in Uganda about adherence to antiretroviral therapy done among economically vulnerable adolescents, it was found that the distance to the health clinic and the economic situation in the household were amongst the issues raised for non-adherence to ART (Bermudez, Jennings, Ssewamala, Nabunya, Mellins & McKay, 2016:88).

Based on the above discussion, adolescents have to be involved in the planning of their treatment regime in order to identify individual factors that may influence how they take their treatment and assist them in developing strategies to improve adherence.

2.6.4 Participating in decision making and self-regulation

Self-regulation involves decision making, setting goals, planning, and self-efficacy. Adolescents go through different developmental stages and may reach various developmental milestones at different ages. They are expected to become independent adults who eventually leave their parents or caregivers (Satoe, Bal, Roelofs, Bal, Mledema & van Staa, 2015:14)

Self-regulation also involves motivating oneself and to self-reflect. Having a chronic condition complicates the development of friendships and school participation, as for example, hospitalizations/clinic attendance and disclosure issues may stand in the way (Sattoe et al., 2015:14). Adolescents need to get involved in their own care by, for example, drawing up an action plan, focusing on illness needs, activating resources, dealing with symptoms, and they need to realize when and how to ask for support (Sattoe et al., 2015:81). The voices and concerns of adolescents and young people need to be heard by care providers. Youth-centred and youth-led approaches that engage young people in the planning, implementation and evaluation of programmes are needed. Adolescents have a greater need to be consulted about their own care due to their developmental stage.

2.6.5 Support

Support involves giving assistance to adolescents managing a chronic disease. The resources that adolescents can engage in to assist with or facilitate self-management are mostly the family and health facilities (Sattoe et al., 2015:14). Support groups provide a valuable opportunity for HIV-positive adolescents to share information, mitigate the effects of stigma, and to learn from and provide support to each other (UNICEF, 2016:5).

Adolescence is a time when the responsibility of the caregiver decreases, and adherence becomes the sole responsibility of the adolescent (Malee, Williams, Montepiedra, Mc Cabe, Nichols Sirois, Storm, Farley & Kammerer, 2011:192). Perinatally-infected adolescents often face obstacles with their functional autonomy. Due to being infected with HIV at an early stage and the long-term use of ART, they may develop physical and developmental disabilities. This may also cause the adolescents to be more dependent on their family (MacDonald, Naar-King, Huszti & Belzer, 2013:92).

Stronger parental, caregiver and community support have been shown to enforce better adherence among African ALHIV. More family and household centred approaches are able to address some of the broader barriers to adherence. For example, these centred approaches may strengthen caregivers' knowledge and skills and reinforce the protective influence of a caring and supportive caregiver and adolescent relationships (Winskell, Miller, Allen & Obong, 2016:2). In many families the youth are reminded to take their treatment by family members. The family also provides the youth with emotional support and reasons to take the medication (Winskell, Miller, Allen & Obong, 2016:2).

Peer groups play a key role in enhancing psychosocial support. A study that was done in Zimbabwe about disclosure to perinatally-infected adolescents found that adolescents learned a great deal about HIV/AIDS and its complications from their more experienced peers during

peer support groups and sharing sessions (Kidia et al., 2014:3). In some areas the clinic-sponsored groups for ALHIV are seen as an opportunity to make new friends, encourage each other and hear about the experiences of other ALHIV (Ferrand, Simms, Dauya, Bandason, Mchugh, Mujuru, Chonzi, Busza, Kranzer, Munyati, Weiss & Hayes, 2017:181).

Support can also be from the community. Community-based approaches such as youth adherence groups, and support by community health workers to support retention in care and adherence, are being promoted to contribute to adherence to treatment. Community-based approaches were found to be an effective adherence intervention to improve viral suppression in children and adolescents. Community-based interventions need to be scaled up and careful attention needs to be paid to the training and mentoring community of workers (Ferrand et al., 2017:181).

2.7 Interventions to improve self-management

The prognosis for children and ALHIV has changed in that they can live long and healthy lives. Paediatric care providers need to work with adult care providers to ensure that the patients are prepared for an independent and a healthy life (Lee & Hazra, 2015:2). With the implementation of well-prepared plans, children and youths will feel more comfortable to make the transition to adult care (Lee & Hazra, 2015:2). Self-management programmes focus on improving self-efficacy and skills such as problem-solving, setting goals and evaluating one's own care (Schulman-Green, Jaser, Martin, Alonzo, Grey, McCorkie, Redeker, Reynolds & Whittemore, 2012:137). These skills should be taught to adolescents.

If the transition from childhood to adolescence and adolescence to adulthood are done correctly, the adolescents may feel that they can manage their illness, therefore seeking and attending their medical appointments. Furthermore, they may become goal-orientated toward healthy and long-term living (Lee & Hazra, 2015:1). Transition plans need to look at adolescents' needs and target adolescents by integrating adolescent-friendly healthcare services into a comprehensive care model (Lee & Hazra, 2015:2). Adolescent-friendly health services (AFHS) must be tailored to adolescent needs (WHO, 2009:34).

The characteristics of AFHS are that adolescent-friendly policies need to be implemented and should include gender awareness, guarantee privacy and confidentiality. Adolescent-friendly procedures need to ensure that the waiting times are shorter and health workers and support staff must be trained to provide services for adolescents. Adolescent involvement is also a characteristic of AFHS. The adolescent needs to be adequately informed about the services and their rights and they should be included in the assessment of the services (WHO, 2009:35). The adolescent period includes skills development for future planning, planning a

career and intimate relationships. Therefore, programmes have to be designed or established to assist the HIV-infected adolescent to become productive adults (Lee & Hazra, 2015:2).

2.7.1 Adolescent focused programmes to improve self-management skills

The Southern African HIV Clinicians Society (2017:5) advice about certain aspects to improve adherence amongst adolescents. These are the involvement of parents or caregivers; the management of disclosure; the use of support groups; and the provision of adolescent- and youth-friendly services. Young people need to know that they have the love and support of their parents or caregivers, and should be supported and guided as they move through different stages of adolescence into adulthood (Southern African HIV Clinicians Society, 2017:5). Disclosure assists the young person to come to terms with and understand, what it means to live with HIV. Support groups provide a valuable opportunity for HIV-positive adolescents to share information, mitigate the effects of stigma, and to learn from and provide support to each other. Effective adherence support needs to take place within the context of services sensitive and responsive to the needs of adolescents and youth living with HIV (Southern African HIV Clinicians Society, 2017:6).

Historically, evaluation of HIV/AIDS treatment programmes in resource-limited settings has focused on adults and/or children and adolescents have been overlooked. As HIV-positive children mature, it is important that appropriate services are available to counsel them on sexual safety, adherence to ART and reproductive choices (Evans et al., 2013:1). Targeting the developmental period of adolescence and focusing efforts of improving HIV care services will facilitate transitioning children to adolescence and adolescence to adult care in a more effective way.

Adolescents may thus feel clinically and psychosocially able to manage their HIV illness, seek and attend appropriate medical appointments and may become goal-orientated toward healthy and long-term living (Lee & Hazra, 2015:2). Additional needs for successful transition plans should also include an assessment of the young adult's educational aspirations, with appropriate vocational and life skills. The adolescent period includes development for future planning, planning a career, and intimate relationships. Therefore, programmes have to be designed or established to assist the ALHIV (Lee & Hazra, 2015:2). In a study that was done in Thailand to understand the factors associated with high rates of ART medication adherence among youths living with perinatal HIV, it was found that the adolescents have a high level of self-efficiency. They have a capacity to follow a daily medication regimen. The adolescents' beliefs, attitudes, motivation and behavioural skills and resources influence them to consistently follow a medication regimen. It was also established that the Thai-Buddist cultural

script that plays a role in social and family obligations, further motivate the development of efficiency in adhering to medication (Kang, Delzell, Chhabara & Oberdorfer, 2015:539).

Another study was done in Haiti among ALHIV aged 13 years to 19 years. The adolescents were enrolled in adolescent friendly facilities. The results were that implementation of a youth friendly adolescent HIV clinic can improve outcomes, particularly in the first six months after being newly diagnosed (Reif, Betrand, Benedict, Lamb, Rouzier, Verdier, Johnson, Page, Fitzgerald, Kuhn & McNairy, 2016:26). Yet another study about transition of care was done in the United States. Fourteen sites were identified for this study. The study showed how difficult the process of transition for HIV-positive adolescents is. The outcome was that youth friendly clinical environments may reduce the unique barriers to care faced by HIV-positive adolescents such as non-adherence and stigma (Tanner, Philbin, Duval, Ellen, Kapogiannis & Fortenberry, 2014:8).

In an article review on the effectiveness of self-management education programmes to improve physical, psychosocial, health knowledge, and behaviour outcomes for PLHIV, sufficient evidence was found to infer that self-management programmes for people living with HIV/AIDS result in short-term improvements in physical, psychosocial and health knowledge and behavioural outcomes (Milliard et al., 2013:110). However, the effect of programmes to improve self-management skills amongst ALHIV has not been determined.

2.8 Conclusion

In South Africa a limited number of studies have been conducted on how to transition HIV-positive adolescents to adult services and to establish adolescent-friendly programmes to encourage ALHIV to self-manage their illness effectively. Establishing these adolescent-friendly programmes will assist adolescents in planning for the future, for education, marriage and pregnancy. Many adolescents and those perinatally infected are reaching adolescence due to effective ART. HIV-positive adolescents are currently being left behind and differentiated care strategies are needed to ensure that global and national care targets are reached amongst this group. In order for the programme to be optimally effective, it needs to be based on the self-management needs of adolescents.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

The previous chapter described the background of the study and a literature review about the self-management skills and needs of ALHIV. In this chapter the research methodology is described in detail.

The research methodology of a study informs the reader how the investigation was carried out (Brink, van der Walt & van Rensburg, 2012:102). In other words, it reveals what the researcher did to solve the research problem or to answer the research question.

3.2 Aim and objectives

The aim of the research was to explore the self-management needs of adolescents who live with HIV in the Nelson Mandela Bay area of the Eastern Cape in order to make recommendations that can be used to develop a programme to support adolescents to self-manage their illness.

3.3 Objectives

The objectives were to:

- Explore adolescents' beliefs, knowledge and understanding of their illness.
- Describe the self-regulation skills and abilities of adolescents.
- Identify the resources adolescents utilise to facilitate them to manage their illness.

3.4 Study setting

The setting is the area where the study is conducted (Burns & Grove, 2011:40). The study setting of this study was done in a natural setting, at the clinic where they were recruited or a place of their choice, because the adolescents described their experiences, and needed to feel comfortable in doing so.

There are eight districts in the Eastern Cape. The research was conducted in the Nelson Mandela Bay District. This district is an urban district (Figure 3.1).



Figure 3.1: Map of the Eastern Cape Municipalities

(Source: Nelson Mandela Bay Health District Operational Plan, 2018-2019)

There are three sub-districts in the Nelson Mandela Bay District, namely, sub-district A, sub-district B and sub-district C. There are 12 clinics in sub-district C. The study was conducted in sub-district C, at West End and Booyesen Park Clinic. They are primary health care clinics that deliver a range of services such as chronic services, ante natal services, antiretroviral services and immunisation services.

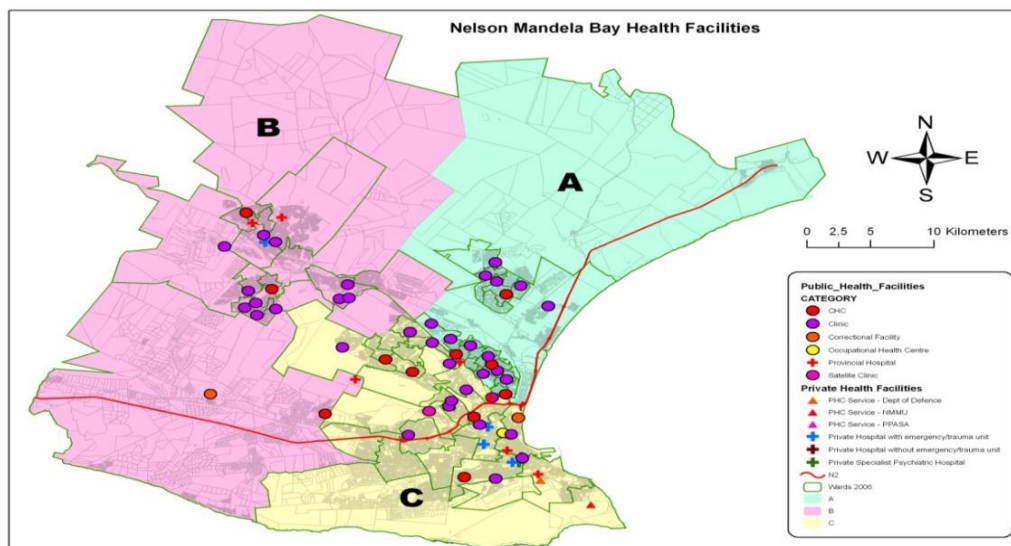


Figure 3.2: Map of Nelson Mandela Bay sub-districts

(Source: Nelson Mandela Bay Health District Operational Plan, 2018-2019)

3.5 Research design

A research design is a blueprint for conducting a study. The design allows the researcher to control factors that can interfere with the validity of the study findings (Burns & Grove, 2011:251). A qualitative, descriptive research design was applied to explore the self-management needs of adolescents living with HIV in the Nelson Mandela Bay Area.

3.5.1 Qualitative research

By using a qualitative research approach, the researcher wanted to focus on the self-management skills and needs of HIV infected adolescents. Qualitative research is a systematic, subjective approach used to describe life experiences and give them meaning (Burns & Grove, 2011:73). The findings from a qualitative study lead to an understanding of a phenomenon in a particular situation and are not generalised in the same way as quantitative studies (Burns & Grove, 2011:73).

The researcher used a qualitative research approach, using interviews in order to understand the phenomenon that are being researched. By using a qualitative research approach, the life experiences of the participants are described. Further, as a nursing researcher, the researcher must reflect on how the findings might be useful to practicing nurses. Understanding the self-management skills and needs of ALHIV may be helpful to nurses in providing care for this vulnerable group. The reasoning process used in qualitative research involves perceptually putting pieces together to make wholes. From this process, meaning is produced. Perceptions vary with different individuals, therefore many different meanings are possible (Burns & Grove, 2011:74).

3.5.2 Descriptive research

Descriptive research examines characteristics of a single sample (Burns & Grove, 2011: 257). In order to gain more information about characteristics within a particular field of study, a descriptive study design is used. A descriptive design may be used to develop theories and identify problems with current practises. No manipulation of variables is involved in a descriptive design. According to Polit and Beck (2018:191), a descriptive qualitative study does not have roots in a particular qualitative tradition, involves the collection of rich qualitative data and often uses content analysis. Descriptive designs may be used to identify problems with current practice, to justify current practice, make judgements or to develop theories (Brink, van der Walt & van Rensburg, 2012:112).

A descriptive approach was used by the researcher to collect data. Through the process of developing a qualitative study, researchers become familiar with published theories and research related to the phenomenon that is being studied (Burns & Grove, 2011:75).

The researcher was actively involved in the interviews with the participants. The information was gathered using open-ended questions and semi-structured interviews that allowed the participants to answer freely and the researcher to summarise and reflect on what the adolescent said.

3.6 Population and sampling

The population is all individuals that meet certain criteria for inclusion in a study (Burns & Grove, 2011:51). The population of the study was all HIV positive adolescents in the age group 14 years to 19 years, attending the West End and Booysen Park clinics. The total population of HIV positive adolescents in the age group 14 years to 19 years at West End clinic was 30 and at Booysen Park clinic 35. The average number of adolescents who attended the clinics monthly was 15 at the West End Clinic, and 25 at Booysen Park clinic. Adolescents on ART receive two-monthly appointments for monitoring adherence. The average number of adolescents who attended the clinics monthly was 8 at the West End Clinic, and 12 at Booysen Park clinic (see Table 3.1).

Table 3.1 Sample demographics

Variable	n (%)
Gender	
Male	4
Female	8
Race/ethnicity	
Coloured	5
Black	8
Age	
14-15	4
16-7	3
18-19	5

3.6.1 Sampling

A sample is a subset of the population that is selected for the specific study (Burns & Grove, 2011:51). Sampling defines the process of selecting a group of people, behaviours, events or

other elements with which to conduct the study (Burns & Grove, 2011:51). The sample is determined by whatever the researcher wants to know about the phenomenon.

Participants who were recruited for this study were appropriate to answer the research question, and they had similar experiences as set out in the inclusion criteria. They were chosen because they were adolescents living with HIV and had experience in managing their illness.

In the study, purposive sampling was used to select two clinics that have a high number of ALHIV attending services in comparison with the other clinics in the district. Purposive sampling is sometimes referred to as selective sampling. The researcher consciously selects certain participants to include in the study. The ultimate goal of purposive sampling is selecting information-rich cases from which researchers can obtain in-depth information needed for their studies (Burns & Grove, 2011:313). The researcher chose to interview adolescents in the age group 14 years to 19 years, because of their cognitive maturity. It was assumed that adolescents in this age group would be able to articulate their self-management needs.

The researcher planned to use age, race and gender as sub-groups to select participants to ensure representativeness and variability. It was planned to include five participants from the age group 14-16 and five from the age group 17-18; five Coloured and five Black (African) participants; and five males and five females. However, it was challenging to include an equal number of participants in the age categories. There were adolescents in the age categories on the record at the clinics, but most of them were defaulting treatment.

The researcher approached twenty one participants to be included in the study. There were two behaviourally-infected adolescents that were already twenty years old and therefore did not qualify for inclusion in the research study. Two potential participants age fifteen and sixteen years were handed consent forms to give to their guardians so that they could grant consent for the adolescents to participate in the study. The adolescents did not return with the consent forms. Another sixteen year old adolescent and her mother, signed the consent forms and an interview date was scheduled. However, before the interview could take place, the adolescent died of Pulmonary Tuberculosis. One guardian that collected her fifteen year old daughter's treatment was approached, but refused permission for the researcher to talk to the adolescent. She stated that she did not want people to talk about HIV with her daughter. Another sixteen year old adolescent's guardian was approached to ask for permission to include her sister in the research study, but she told the researcher that she had not yet disclosed to the adolescent about her HIV status. The researcher advised the guardian to disclose to the adolescent. With the help of the psychologist at the clinic, the guardian and the

adolescent were assisted with disclosure, and the adolescent was eventually told about her HIV status by the guardian in the presence of the psychologist. However, she was not included in the study. One adolescent was excluded because of intellectual disability. She was 14 years old but was unable to answer questions in a coherent manner. The adolescent attended a special school.

Due to the challenges explained above, the sample size was determined by the emerging themes in the interviews and data saturation and not by inclusion of the identified sub-groups. Thirteen interviews were conducted, inclusive of the pilot interview. For this study, saturation of data occurred with the 13th interview when the data became repetitive and redundant and subsequent interviews provided no new information (Burns & Grove, 2011:372).

3.6.2 Inclusion criteria

The inclusion criteria are the characteristics that the subject or element must possess to form part of the target population (Burns & Grove, 2011:291). This was as follows:

- Adolescents 14 – 19 years: The cognitive development skills such as problem solving, which is key for self-management, are more developed and they are more likely to have their status disclosed to them (WHO, 2009:16).
- Adolescents must be HIV-positive.
- They must attend the West End clinic and Booyesen Park clinic.
- The adolescents must know that they are HIV-infected, since they cannot self-manage unless their HIV status are disclosed to them.

3.6.3 Exclusion criteria

The exclusion criteria are those characteristics that can cause a person or element to be excluded from the target population (Burns & Grove, 2011:291). This was as follow:

- Adolescents with any severe intellectual disability that compromised their ability to self-manage and who were unable to answer questions in a coherent manner. These adolescents may need additional support with self-management.

3.6.4 Gaining access to the study population

Prior to the data collection, the researcher sent an email to the governance department at the Nelson Mandela district health department. The approval letters from the ethics committee at Stellenbosch University and the Eastern Cape Department of Health were attached. The researcher also contacted the coordinator of the sub-district C clinics, who gave verbal permission. The researcher informed the operational managers of the West End and Booyesen Park clinics verbally and they gave permission for access to the adolescents.

The researcher visited the clinics in the afternoon, as most of the participants were at school and came to the clinic after school. The participants were referred to the researcher by the respective nurses involved in the care of the participant. Where the guardian collected the medication for the participants, written consent was obtained from the guardian. If a participant between the ages of fourteen and seventeen came alone to the clinic, a consent form was sent with the adolescent for the guardian to read in order to give consent. The guardians were contacted by phone and informed about the study. An opportunity was provided to ask and answer questions if the guardian had any. The adolescent brought the signed guardian consent form with them to the researcher, and a date and time were scheduled for the interview to take place. The research objectives were discussed with the adolescent, consent was then obtained from the adolescent, who was then asked to sign the assent form. Participants who were eighteen or nineteen years old gave consent themselves after the study was explained to them. Three participants stayed in a home for children affected by HIV. Their interviews were conducted at the home, by the researcher. Verbal permission was obtained from the director of the home, and the social worker. Five of these participants was above the age of eighteen years, therefore they gave consent for themselves. The other participant was fourteen years old and consent was signed by her "housemother" who, according to the policy of the place of safety, acted as her guardian.

A time convenient for the participants was arranged. The researcher explained the aim of the study to the participant and the importance of the confidentiality of their information. The researcher ensured that the inclusion criteria were followed, and that all participants knew their HIV status. After the researcher introduced herself to the participants, interviews were conducted in a pre-arranged place.

3.7 Interview guide

The interview involves verbal communication between the researcher and the subject, during which information is provided to the researcher. This data collection strategy is most commonly used in qualitative and descriptive studies (Burns & Grove, 2011:350). In this study the researcher used semi-structured interviews to allow the participants freedom to talk about their self-management needs, while the researcher still controlled the interview.

In order for the researcher to get all the information from the participants, an interview guide (appendix 6) was used with open-ended questions that was based on the objectives of the study and the researcher's experience.

Each interview was started with demographic questions about the age and grade of the participant. The questions were then followed by questions about their experiences at the

clinics, when they had learned about their HIV-positive status, and how they take care of themselves. Questions included for example, “Tell me more about your future plans.” Probing questions were asked by the researcher.

3.8 Pilot interview

The researcher conducted a pilot interview with a 19 year old adolescent attending Booyesen Park clinic. The pilot interview was done to test if the questions asked were clear. It was also used to refine the interview skills of the researcher. The pilot interview was audio-recorded. The participant was able to answer the questions that were asked. The audio recording was sent to the study’s supervisor, who assessed the interview skills and provided feedback. The feedback from the supervisor was that the interview was too short and that the researcher could improve the depth of the information by probing more. More probing questions were added to the interview guide. Although the pilot interview was short (10 minutes) it yielded valuable data and was included in the analysis.

3.9 Scientific rigour of the study

Rigour was ensured by applying the principles of trustworthiness. Trustworthiness is concerned with the accuracy and truthfulness of scientific findings (Brink et al., 2007:118). Four criteria that are used to ensure trustworthiness of a study are credibility, transferability, dependability and conformability.

3.9.1 Credibility

Credibility refers to the confidence in the truth of the data and its interpretation (Brink et al., 2007:172). The researcher must strive to establish confidence in the truth of the findings for the particular participants and context in the research (Polit & Beck, 2012:585).

Strategies to enhance credibility are prolonged engagement, reflexivity, triangulation, recording of information and member checking (Polit & Beck, 2012:589-591). These strategies are described below.

3.9.1.1 Prolonged engagement

Prolonged engagement is the investment of sufficient time collecting the data to have an in-depth understanding of the people under study (Polit & Beck, 2012:589). The researcher is working at the Chatty Clinic (a clinic in the same sub-district where the study was conducted), and has experience in providing services to adolescents living with HIV and thus had prior knowledge of their experiences.

3.9.1.2 Reflexivity

Reflexivity implies that the researcher explores personal feelings and experiences that may influence the study, and integrates this understanding into the study (Burns & Grove, 2011:95). The researcher kept a reflexive diary while conducting the interviews. The researcher also used the diary to bracket her personal feelings and experiences about the phenomenon from the time of the development of the proposal. By keeping a reflexive diary, the researcher got to perceive the experiences through the eyes of the participants (Polit & Beck, 2012:589).

3.9.1.3 Recoding of information

The researcher prepared thoughtful field notes that were rich in descriptions of what transpired in the field (Polit & Beck, 2012:591). Semi-structured interviews were performed until data saturation occurred. The interviews were audio-recorded, and field notes taken. This allowed for an audit trail that could be reviewed by an independent auditor (Polit & Beck, 2012:591).

3.9.1.4 Member checking

Member checking can be used to correct obvious errors and to provide additional information (Brink et al., 2007:172). The researcher can do member checking through probing to ensure that the participant's meanings were understood (Polit & Beck, 2012:591). Member checking was done by summarising the statements of the participants during the interviews, and allowing the participants to confirm the truth about the statement.

3.9.1.5 Peer review/debriefing

The researcher regularly spoke to peers, who are experts, outside the study. The researcher received advice from the supervisor, who has more experience about the phenomenon (Brink et al., 2017:172).

3.9.2 Transferability

Transferability is the extent to which findings can be transferred to other settings (Polit & Beck, 2012:585). Within qualitative research, demonstrating transferability of findings lies with those who wish to apply it in another context. Strategies to enhance transferability include thick descriptions, purposive sampling and data saturation (Brink et al., 2007:173).

The setting was described in detail in the study setting section and again in the presentation of the findings in Chapter 4. The researcher ensured transferability by applying the inclusion criteria when recruiting participants. Purposive sampling was used to select participants to increase the range of information collected. The data was presented by providing thick descriptions of the participants and their context.

3.9.3 Dependability

Dependability refers to the stability of data over time (Brink et al., 2007:173). It asks the question of whether the findings of an enquiry will be repeated if it were replicated with the same participants in the same context.

Stability was enhanced by using an interview guide to ensure that all interviews were done in the same manner. The audio-recorded data were transcribed by the researcher. There is also an audit trail kept between the supervisor and researcher, such as electronic mail. The supervisor also checked the coding and themes.

3.9.4 Confirmability

It is concerned with establishing whether the data represent the information provided by the participants, and that the interpretations of the data are not fuelled by the researcher's imagination. The data must reflect the voice of the participants and not the researcher's biases or perceptions (Brink et al., 2007:173).

Transcripts are available on request from the researcher to ensure that conclusions, interpretations and recommendations are correct and can be traced to the source. The supervisor also checked the data analysis process.

3.10 Data collection

Data collection is the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions, or hypotheses of a study (Burns & Grove, 2011:52). The researcher has to obtain permission from the managers of the setting where the data collection will take place. Data collection was done by conducting individual semi-structured interviews, using a semi-structured interview guide (appendix 6).

The researcher provided the participants with an information leaflet about the aim of the study. The study objectives were explained to the participants so that they could know what to expect and be prepared. The researcher gave the participants an opportunity to ask questions. This was done for openness, honesty and to correct misunderstandings (Richie, Lewis, Nicholls & Ormston, 2014:83).

The researcher normally collects data according to the pre-established plan (Brink et al., 2012:57). The methodology selected for this study was one-on-one individual interviews. The researcher is fluent in Afrikaans and English. Some of the participants were speaking Xhosa and English but preferred to conduct the interviews in English. The researcher assessed whether the participants were comfortable enough with English and planned to use an interpreter for the Xhosa speaking participants who were not comfortable. There were two

interviews conducted in Afrikaans and ten interviews were conducted in English. The researcher conducted the interviews herself. There were nine Xhosa speaking participants who preferred the interviews to be done in English, because they are attending English speaking schools, and felt comfortable in expressing themselves in English. First, questions were asked about demographic characteristics like age, grade and interests, to make the participant relax. All participants answered the questions in their own words and reflection was done by the researcher. The interviews were recorded on an audio-recorder, and permission to use an audio-recorder was obtained from the participants before the interview. The data were transcribed in Afrikaans and English by the researcher.

3.10.1 Interviews

Face-to-face interviewing has been claimed to provide a stronger basis for the establishment of good rapport between the researcher and the participant, helping to create an environment where the interviewee can respond in a free-ranging and complete way and where the researcher is able to take non-verbal communication into account (Richie et al., 2014:182).

There are skills and attributes involved in conducting interviews. Active listening is one of the skills that is fundamental to the interview interaction. This does not just mean listening to the words but really trying to hear the meaning of what the participant is saying. The researcher identifies where there is subtext that needs to be explored, thinking about what has not been said, and hearing the nuances in the participant's account (Richie et al., 2014:185).

During the interview the participants had the right to answer questions. A semi-structured interview guide was used. They were not hurried to answer questions, and were given time to think before they answered. The participants were made to feel comfortable and respected during the interview. In each interview the participants expressed themselves freely and in their own words. The researcher summarized and reflected on the participants' words during the interviews and the participants had an opportunity to verify the contents of the interview to fulfil the requirements of member-checking, thus enhancing the credibility of the data. Participants were given the opportunity to give their own views and left without negative feelings about the interviews (Richie et al., 2014:83).

The interviews were conducted over three months, and field notes were taken during the interviews by the researcher. Member checking was performed during the interviews. The duration of the interviews was between 20 and 40 minutes and information was transcribed by the researcher. Although the researcher was a female and older than the adolescents, she did not experience difficulty in interviewing the adolescents. Boys and girls equally verbalized their experiences. However, older participants aged 17 to 19 were more open and answered

the questions in detail, whilst the younger participants aged 14 years to 16 years had to be probed to answer questions.

3.11 Data analysis

Data analysis involves converting masses of data into smaller, manageable segments. Analysis involves discovering pervasive ideas and searching for general concepts through an inductive process (Polit & Beck, 2012:562). Interviews were transcribed in a Microsoft Word document. The researcher used the steps described by Creswell (2014) for data analysis.

After the interview the rights of privacy and anonymity were maintained. The audio-tapes were anonymous. The transcripts were each given a pseudonym and were kept on a password-protected computer. Unbiased and accurate reporting was done.

3.11.1 Creswell's approach

There are six steps to Creswell's (2014) approach and these are the following:

1. Organize and prepare the data for analysis.
2. Read through the data.
3. Data is coded, that is to organize the data into pieces of information.
4. The coding process is to generate a description of the setting or people as well as categories or themes for analysis.
5. Present the results of the analysis.
6. Interpret the results of the analysis.

3.11.1.1 Organize and prepare the data for analysis

All the audio-files were labelled with the date and time of the interview, the age, and if it was a male speaker or female speaker. A pseudonym was given to each participant. The audio-files were destroyed by the researcher, once the transcripts were verified. The researcher did a verbatim transcription. The transcripts and the audio-tapes were labelled the same. The data were arranged and sorted according to topics. The researcher typed field notes and sorted and arranged the data into different types, depending on the source of information (Creswell, 2014:196).

3.11.1.2 Read through the data

The researcher then read through the data. By doing this, the researcher experienced a general sense of the self-management needs of the ALHIV. These general ideas about the data were then written down (Creswell, 2014:196). The researcher reflected on the overall

meaning of the data. This included a reflection on the general ideas participants were sharing, the tone of the ideas and the impression of the overall depth, credibility, and use of the information (Creswell, 2014:106).

3.11.1.3 Coding of the data

Data were coded by organising the data into pieces of information and writing a word that represents a category in the margin. During the coding process, the researcher presented a detailed description of the setting or the people involved as well as descriptions of the categories or themes for analysis (Creswell, 2014:196). Coding was done according to the study objectives.

3.11.1.4 Description of the setting or people and categories or themes for analysis

The researcher used the coding process to describe the setting that was used, and the people and the themes to prepare it for analysis. The themes are the ones that appear as major findings in study. These themes will be used as headings in the finding sections of the study. The researcher will interconnect the themes into a story line (Creswell, 2014, 2014:196).

3.11.1.5 Present the results for analysis

The next step is that the researcher presents the results of the analysis. This may include a chronology of events, detailed discussion of several themes or a discussion of interconnecting themes. The researcher completed sub-themes, specific illustrations and quotations (Creswell, 2014:200).

3.11.1.6 Interpret the results of the research

The results of the analysis are interpreted by asking questions such as “what were the lessons learned?” This helps the researcher to use the findings to make recommendations for developing a programme that can support adolescents with self-management (Creswell, 2014:196-200). The researcher described how the narrative outcomes compared with theories and the general literature on the topic. The researcher used peer debriefing by sharing the findings with the study supervisor (Creswell, 2014:202). The supervisor reviewed every step of the analysis as well as the presentation of the findings and interpretation. The outcomes of the findings are described and compared with literature on the topic and presented in chapter 5.

3.12 Summary

The researcher used a qualitative descriptive research approach. Purposive sampling was done, where ALHIV were purposefully selected to form part of the study. The inclusion and exclusion criteria were used to ensure that the participants, who were selected, could answer

the interview questions. Rigour was ensured by applying the principles of trustworthiness; that is, credibility, transferability, dependability and conformability. The data collection method in the form of interviews was chosen. Data analysis was done according to the six steps of Creswell, as described in Section 3.11.1 above. The research findings will be discussed in the next chapter.

CHAPTER 4

FINDINGS

4.1 Introduction

The findings of the research are discussed in this chapter. The discussion is structured according to the themes and sub-themes induced during data analysis. Verbatim participant quotations are provided to substantiate the interpretation.

4.2 Section A: Biographical data

The demographic profile of the participants was considered since it provides a background to the characteristics of the participants. The participants were a mix of male and female, Coloured and Black (African) participants. There were five Coloured participants and eight Black (African) participants. Two participants were behaviourally infected with HIV and eleven participants were perinatally infected. Four participants were fourteen years old, two were sixteen years old, one was seventeen years old, two participants were eighteen years old and four were nineteen.

4.3 Section B: Themes emerging from the data analysis

In this section, the findings of the research are presented in the form of themes and sub-themes. Table 4.1 summarises the analysis outcomes. The findings will be discussed under the headings: Beliefs, knowledge and understanding; self-management skills and abilities; and resources that facilitate self-management. These headings were the study objectives.

Table 4.1: Themes and sub-themes

4.3.1 Beliefs, knowledge and understanding	
Themes	Sub-themes
Lack of knowledge	Limited knowledge about how they became HIV infected Limited knowledge about HIV Limited knowledge about safe sex
Sources of information	Sourcing information from the internet, family and friends
Feelings about HIV	Negative feelings about HIV Positive feelings about HIV
Self-esteem	Good self-esteem

4.3.2 Self-management skills and abilities

Themes	Sub-themes
Disclosure	Keeping their HIV status a secret Decisions about disclosure
Managing stigma	Feelings about stigma Managing stigma in the communities
Taking treatment	Managing treatment
Coping mechanisms	Individualised coping
Communication	Inability to communicate with guardians, parents or healthcare workers
Goals	Future plans Plans to reach goals

4.3.3 Self-management resources

Health facilities	The facilities are not conducive for adolescents The time spent at facilities
Healthcare workers	Relationship with healthcare workers
Family and friends	Family and friends support the adolescent to cope with HIV Family support in taking treatment

4.3.1 Beliefs, knowledge and understanding

Believing and knowing includes views and ideas about one's illness, the future and confidence to self-manage (Ryan & Sawin, 2009:124). It may also include how to navigate the healthcare system and an understanding of the importance of treatment (ART). Knowledge in itself does not lead to behavioural change, but if you enhance knowledge or specific health beliefs, it may lead to behavioural change. Knowing about their illness, like what may happen when they do not take their treatment every day, may lead to adherence to ART and viral suppression (Crowley, 2017:269).

The knowledge, beliefs and understanding about HIV are grouped into five themes: lack of knowledge, sources of information, feelings about HIV and self-esteem.

4.3.1.1 Theme 1: Lack of knowledge

The participants showed a general lack of knowledge about HIV. Two adolescents did not have any knowledge of how they became HIV-infected. Some adolescents had limited information about HIV. A number of participants verbalised that they are scared to talk to family or guardians about HIV or matters regarding life. Three sub-themes were identified.

4.3.1.1.1 *Limited knowledge of how they became HIV infected*

An adolescent's HIV status is normally disclosed by the parents or guardian of the adolescent who was vertically infected, for example, through mother-to-child transmission. Adolescents that are behaviourally infected, are informed about their HIV status by a healthcare provider.

Two participants either did not know how they were HIV infected or narrated that they could not remember. These participants were 14 years old. The one participant was staying with his grandfather and appeared to have very limited information about his illness. The other participant resided with her aunt, who apparently did not know how the child became infected.

No I don't know how I got HIV. (Participant 10, 14 year old male)

On the other hand, most of the older adolescents knew how they acquired HIV.

4.3.1.1.2 *Limited knowledge about HIV*

There were three participants who indicated that they have limited knowledge about HIV. These adolescents stayed with either a grandmother or guardian. They did not feel comfortable talking about HIV with their guardian or grandmother. The one participant found out about her HIV status when she was 12 years old, at the time that she came to stay with her aunt. Her aunt has no information about the adolescent's biological mother. The adolescent narrated that she was just told that she was HIV-infected and that she had to take treatment. One participant stays in a home for children infected or affected by HIV/AIDS and indicated that they never discuss HIV in that setting. The children are told that they are HIV-infected, but in general HIV is not discussed and they also do not ask questions. The third participant stayed with her sister and was only recently disclosed to. She was not told about HIV by her mother and had no knowledge about HIV as she was also just told to take the treatment. After her mother died her sister told her that she is HIV-positive, because the participant started to ask questions about the treatment that she is taking.

No I don't know anything about HIV. (Participant 9, 14 year old female)

I don't know anything about HIV, I have to find out for myself. (Participant 13, 19 years old female)

It was apparent that both younger and older adolescents demonstrated limited knowledge as the one participant with limited knowledge was 19 years old. Their lack of knowledge seems to be due to the limited communication with caregivers/guardians because of the various circumstances as described above.

4.3.1.1.3 *Limited knowledge about safe sex*

Knowledge about safe sexual practices such as protection from sexually transmitted diseases and the use of family planning becomes increasingly important during adolescence. Whereas some adolescents knew about safe sexual practices, others did not know or had limited knowledge. It was particularly the young participants who verbalised a lack of understanding about safe sex. This may also be because they were too shy or uncomfortable to speak about it.

I don't know anything. (Participant 5, 14 year old female)

Certain adolescents demonstrated an understanding of safe sexual practises such as how to protect their partner from acquiring HIV. However, some participants who were already sexually active, felt pressurised by their boyfriends/girlfriends to have sex without condoms or found it difficult to negotiate condom use.

You must use a condom when you sleeping with a boy. (Participant 7, 14 year old female)

I feel uncomfortable around my boyfriend, and he always ask why don't we do it without a condom because we are first lovers, and I always have excuses.
(Participant 11, 19 year old female)

4.3.1.2 **Theme 2: Sources of information**

For adolescents to make good decisions about their health, they need information about HIV. The participants mentioned various sources of information.

4.3.1.2.1 *Sourcing information from the internet, family and friends*

A number of adolescents verbalised that they used the internet on their mobile phones at home to search for information about HIV on Google. This included information about the side-effects of treatment or any new information about HIV. Adolescents also got information from family and guardians. A few participants mentioned that they receive information from a close friend and others also mentioned getting information from the teachers or library at school.

I go to Google, mostly I used Google most of the time, but I also go to the library sometimes to study things that I found in Google to study in depth. (Participant 4, 18 year old male)

I get information from the teachers at my school. (Participant 7, 14 year old female)

The adolescents preferred to obtain information in a way that they felt comfortable with. The general feeling was that they were more comfortable searching for information on the internet than asking healthcare workers or caregivers. It was noticeable that only a few of the adolescents reported obtaining information from healthcare workers at the clinic they attended.

4.3.1.3 Theme 3: Feelings about HIV

The participants verbalised a range of feelings about living with HIV. These ranged from negative to positive or a combination of both. The feelings of adolescents have to be considered, so that they can be encouraged to continue taking treatment. Two sub-themes were identified, namely negative feelings about HIV and positive feelings about HIV.

4.3.1.3.1 Negative feelings about HIV

Some of the negative feelings related to how they acquired HIV or the way in which the diagnosis was disclosed to them. One of the participants that was behaviourally infected, felt that she could have made better decisions. She felt angry towards the boy that infected her with HIV. She felt that because of that mistake, she has to take this treatment forever and always come to the clinic to take blood samples. However, she learned to adapt and to accept what happened to her. Another participant stated that she felt bad when she found out that she was HIV infected, because she was the only one; her brother is HIV negative. One participant who had been taking ART for a long time, from the time that she was small, narrated that she was never told why she had to take the treatment. When she found out that she is HIV-infected she felt bad, because the information was withheld from her. She however stated that she is feeling better now that she knows about her status as it is better to know than not to know.

I felt very hateful at first. (Participant 6, 19 year old female)

I felt so hurt because I didn't know. (Participant 7, 14 year old female)

4.3.1.3.2 Positive feelings about HIV

For some adolescents, their feelings about HIV emanated from their acceptance of the illness. They felt that they had to accept it as they did not have any agency to change their situation. One participant found hope in the fact that scientists are still looking for a cure for HIV and how to control or stop the virus. He was aware what will happen if he does not take his treatment, but was not disturbed by the virus that is living in his body since according to him, there is not a lot of information about.

I feel like I have it, there's nothing I can do about it. (Participant 11, 19 year old female)

I don't allow myself to become scared without knowing what this thing can do to me. (Participant 4, 18 year old male)

4.3.1.4 Theme 4: Self esteem

Self-esteem concerns how the participants viewed themselves. Good self-esteem is a value of their own worth. The participants made a decision to have a positive attitude about themselves. They look at the future with positive attitudes that also contributed to their self-esteem. The participants felt that they can reach their potential in life, although they live with HIV. It was apparent that they felt that while people do not know about their status, they do not have to worry about self-esteem issues. In this theme, one sub-theme was identified.

4.3.1.4.1 Good self esteem

Living with HIV did not appear to influence their view about themselves in a negative way. Only one participant verbalised that he felt different because he is HIV positive. The participant is a 19 year old male that is living in a home for children infected or affected by HIV/AIDS and he was perinatally infected with HIV. He felt that he is different than people that is not HIV positive. The participant is slightly intellectually disabled and he went to a special school. He is unable to go to university or college because of his disability. At the time of the interview he was waiting for a reply from a college that is specializing in teaching skills to people with disabilities. One participant felt that her family looked at her differently now that she is HIV positive. She suspected that her aunt may have told the extended family. However, she did not view herself as different to before she was HIV infected.

I don't really look at myself as different. (Participant 2, 18 year old male)

I see myself as the same person I was 5 years back before I discovered.
(Participant 6, 19 year old female)

4.3.2 Self-management skills and abilities

Self-management skills and abilities include planning, goal setting, problem solving and decision making (Ryan & Sawin, 2010:124).

Self-management skills and abilities identified in this study are divided into six themes: disclosure, managing stigma, taking treatment, coping mechanisms, communication and goals.

4.3.2.1 Theme 1: Disclosure

One of the skills an adolescent need is the ability to know to whom and when to disclose their HIV status. Disclosure is generally a sensitive issue due to the stigma attached to HIV. Disclosure to a child that was perinatally infected with HIV needs to happen in phases and it is not a once of process. It needs to happen at age appropriate stages in the life of the child. When they reach the age of adolescence (10 years), full disclosure have to happen. This means that they need to know the name of the virus. Disclosure needs to be done by the guardian or parents if the child acquired HIV perinatally. Healthcare workers also have to be involved in disclosure. They have to encourage the guardians or parents to disclose. Disclosure may have an impact on adherence to treatment. As adolescents start to engage in deep friendships and romantic relationships, the need arises for them to disclose their status to people outside their immediate family. There were two subthemes identified: Keeping HIV status a secret and decisions about disclosure.

4.3.2.1.1 *Keeping HIV status a secret*

Some of the participants felt that the disease is a personal issue and nobody else's business. They also did not feel the need to disclose to anyone. It was apparent that the HIV status of the participants were not shared outside the family. The one adolescent that were engaging in sexual relationships did not disclose her HIV status to her partner.

Participants were also told by their family not to disclose their HIV status to people outside the family. Disclosure of their status to persons outside the family without their knowledge made them feel vulnerable. The aunt of one participant told the teacher and the principal at the school about her HIV status. Although the participant felt uncomfortable with this, she mentioned that the teacher and principal did not treat her differently.

About first I was very cautious, I was small when she told me and said I shouldn't tell anyone and so at that time all I felt was that I should not tell anyone because it is no one's business. That is all I felt that I have to keep it secret. Its mine no-one else's and I never felt the need to tell anyone. (Participant 4, 18 year old male)

4.3.2.1.2 *Decisions about disclosure*

The participants also narrated how they made decisions about disclosure, especially in the context of relationships. Some of the older participants felt that if they meet someone that they want to have a relationship with, they have to disclose their HIV status to the person. However, they felt that they first have to trust the person before they can disclose their HIV

status. They wanted to make sure that the person is sincere and that they want to spend their lives with the person.

I will hide it for a bit until I trust the person then I will tell him or her that I am HIV positive. (Participant 11, 19 year old female)

Other participants disclosed their status in the context of the school. One participant had to disclose his HIV status when he went on a leadership camp with the school. He had to disclose if he has an illness or taking treatment on the application form. However, he only shared the information because he knew it will be treated confidentially. Another participant disclosed to the teacher at school after she was told by her sister that she was HIV positive, in an attempt to gain information and support. She wanted to talk to someone, and she spoke to the Life Orientation teacher. This participant took treatment from the time that she was small, but nobody told her why she is taking this treatment. When her mother died in February 2018, her sister told her that she is HIV infected. She was shocked and spoke to the Life Orientation teacher to get more information. She verbalised that she felt better after she spoke to the teacher about her HIV status and that she is still getting advice from the teacher.

Every person have to sign a form for allergies, diseases and certain stuff, but it was like classified as confidential, it was not shared with others. That was the first time I disclosed. (Participant 4, 18 year old male)

I asked "Teacher is there no one staying with you with HIV?" then she say no. I ask about HIV and AIDS what it is about. Then she told me. She asked who have HIV, and I say me. (Participant 7, 14 year old female)

4.3.2.2 Theme 2: Managing stigma

One of the more difficult self-management tasks is dealing with stigma. Participants verbalised that stigma is still persisting in communities. Friends of the adolescents also ask what they are doing at the clinic so often, so they have to lie, because of stigma. They had various ways in which they managed stigma. This theme was divided into two sub-themes, namely feelings about stigma and managing stigma in communities.

4.3.2.2.1 Feelings about stigma

The participants reported instances of stigma in the communities where they reside. Participants felt that they would be discriminated against if other people found out about their status and they recalled conversations where people spoke about HIV in a negative manner. The participants did not experience stigma against them, but towards other people. They felt that if people find out about their HIV status, they will treat them differently. They experienced

that people generally associate certain signs such as pink lips with HIV. One of the participants verbalised that in her community when people have the skin of their lips off and the lips appears pink, the community associates it with being HIV positive. The community belief is that HIV is eating the skin from the lips.

It will hurt if other people know, they will joke about it. (Participant 10, 14 year old male)

Yes, they talk a lot, especially about my boyfriend, the one that gave me the virus, people talk about him, there were times when people used to ask me if I am not scared to be with him. I felt very bad. (Participant 6, female, 19 years)

4.3.2.2.2 *Managing stigma in the communities*

The participants managed stigma differently. Some chose to ignore negative comments or interactions, while others found comfort and security in the fact that their status is secret. There were no indications that the prevailing stigma affected the participants negatively. The participants did not have problems going to the clinic and people seeing them at the clinic.

I just ignore the people that's what I do. (Participant 2, 18 year old male)

I don't worry at all, because they don't know that I have it. (Participant 12, 17 year old female)

One participant related a story of a lady in the community that was infected with HIV by her husband. She apparently did not take treatment and became ill. He felt that there was no reason for her to get sick and wanted to die because there is treatment to use. He saw himself living a healthy life with HIV and that she could also. He was cross with her because he felt that there is no reason for people to die of HIV anymore. This story emphasises young people's frustration with a lack of HIV-positive role models in the community that can foster positive perceptions and reverse HIV stigma.

I first was inconsiderate, how could you allow yourself give up your life because of people's opinions. At first I thought she was stupid, I heard she was really sick. I think like maybe she was not ready to face this thing. We all have different ways to cope and coping mechanisms. Then I appreciate her choice. (Participant 4, 18 year old male)

4.3.2.3 **Theme 3: Taking treatment**

The adolescents who develop good coping mechanisms and experience positive influences, may engage in good health behaviours. Taking antiretroviral treatment (ART) is an important

part in managing the HIV infection in order to maintain good health and control the illness. ART is taken at a specific time every day and daily adherence is important to ensure treatment success. Some of the participants that were older than 15 years, were taking the treatment once at night since the fixed-dose formulation can be prescribed to them. The participants younger than 15 years took treatment twice a day. One participant that was 19 years old, took treatment twice a day, due to being on a second line regimen. The participants felt that they have to take the treatment, that there is no option of not taking it. The participants understood that if they do not take their treatment they will become ill. The theme was divided into one theme; namely, managing treatment.

4.3.2.3.1 *Managing treatment*

Managing treatment included taking treatment daily and integrating it with other routines and activities. Most of the participants knew when to take their treatment. Taking treatment every day from a young age became a burden to some participants. The participants knew when (the times) they must take their treatment and some had ways of how to remind themselves to take treatment. This was especially easier if linked to a specific routine. However, many often struggled to integrate the treatment into their daily routines. Some participants changed their treatment times to fit into their routine. Participants take treatment to school and when it is time to take the treatment they do so. Two participants changed their treatment regime without telling the healthcare workers. The one participant was supposed to take treatment twice a day, but she is taking it at 12H00 in the afternoon and 18H00 in the evening. She said that nobody told her that it is wrong to take the treatment like that. The other participant was also supposed to take her treatment twice a day but she is not taking the evening dose, because it makes her drowsy when she has to study for exams. She is only taking the morning dose at 07H00 in the morning.

I have a phone, then I look at the phone what is the time, when I see it is 12 o'clock then I go fetch water and drink it. (Participant 7, 14 year old female)

I am going in at 7 o'clock [pm] to take my treatment. (Participant 5, 14 year old female)

The participants have ways of taking their treatment when they are with friends or when they are away from home. To prevent accidental disclosure when taking treatment when the participants are with friends, they derived ways of taking their treatment in a way that preserves their secret. This included taking treatment before going to their friends or excusing themselves from the group. Younger and older participants had these strategies of managing their treatment.

I took my treatment before I go out at night. (Participant 6, 19 year old female)

Ya, this one that was last year, it was in Grahamstown then there were lots of us, I made sure they are not seeing me going to the toilet to drink them and come back. (Participant 12, 17 year old female)

4.3.2.4 Theme 4: Coping mechanisms

Coping is a skill that concerns managing HIV, stigma and disclosure. The participants found their own mechanisms to cope, which varied from person to person. Avoidance is mainly used, where they try to avoid the issue, by not talking about it. They feel that they cope if they do not think or talk about HIV. Outbursts and crying were also some of the coping mechanisms that was identified by the participants. Avoiding emotions by focusing on facts and logic was another coping mechanism that was displayed by participants. Some participants were also subconsciously hiding uncomfortable thoughts by avoiding HIV and HIV related topics. One sub-theme was identified.

4.3.2.4.1 Individualised coping

The participants felt that they have to cope with living with HIV as it is not something that they can allow to take over their lives, illustrating their resilience. They found comfort in talking to family or friends when they felt down and needed encouragement to go on. Some participants felt that if they do not think or talk about HIV, they can cope better.

I feel like I have it, I have it, there's nothing I can do about it. (Participant 11, 19 year old female)

I don't really talk, I feel that because it's me, that's the type of person I am. (Participant 2, 18 year old male)

Other participants felt that their religion helped them to cope. One participant had a very strong personality and a positive outlook on life that helped him to cope. He felt that HIV is just a virus that lives in his body, so he is not going to allow it to take over his life. Other participants expressed dealing with negative emotions on their own. They will cry a little and then get up and go on again. Participants were also involved in youth groups and choirs that assisted them in coping.

People used to think I am arrogant, I never felt that people looking at me different, because I was never that kid that sits in the corner feel sorry for themselves, I don't allow myself to do that. (Participant 4, 18 year old male)

I pray first when I feel discouraged. When I am sad, I cry first. Sometimes I cry myself to sleep and think if I made the right decisions before. Then it will pass and I will get up and go on, because giving up is not an option. (Participant 6, 19 year old female)

4.3.2.5 Theme 5: Communication

Young people with a chronic illness have to communicate with caregivers, peers and healthcare workers. Communication between some participants, family and guardians, and healthcare workers was poor. Participants verbalised that it was challenging for them to communicate. One sub-theme was identified.

4.3.2.5.1 Inability to communicate with guardians, parents and healthcare workers

Participants expressed an inability to communicate with their guardian or parent for various reasons. Some mentioned that the parent/guardian reacted negatively before when they wanted to talk about HIV, whilst others felt that they could not be open with their parents about their thoughts and feelings. One participant came to the conclusion that her guardian felt bad because of her HIV status since she always cried when she asks questions. Another participant who is staying with her guardian, felt that her mother who is staying in Gauteng but is still involved in their lives, is treating her like a small child and feared her mother's reaction if she is truthful. Therefore, she was unable to tell her family that she is a lesbian.

But my aunt is a person that is not easy to speak to, because she have a soft heart. So she just cried and I can't stand to see her crying. (Participant 11, 19 year old female)

Yeah not everything, she doesn't know that I am a lesbian. (Participant 12, 17 year old female)

The participants felt that if they talk to their guardian/parent about sex, that the parent/guardian will think that they are engaging in sexual activities. The younger participants felt shy to talk to their guardians about matters related to HIV or life. Some participants who are staying with their grandparents, did not feel comfortable talking about sex with their grandparents.

No she is going to think that I also do it. (Participant 8, 16 year old female)

The lack of communication also led participants to poor disclosure practices as some participants were told at a late stage about their HIV status. One participant found out this year, when she was 14 years old, that she is HIV positive. Her sister told her after her mother died.

I talked to my sister, my sister said I must come and sit down and then she told me that I have HIV and I asked how did I get it and she said I got it from my mother. I felt so hurt because I didn't know. (Participant 7, 14 year old, Female)

Some participants felt that they do not want to ask questions when they are at the clinic; they just want to get their treatment and leave. There are participants that ask questions depending on the clinicians who are consulting them. Some felt because they already sit so long in the line, they do not want to still sit and talk, they just want to collect their treatment and go home. Some will ask questions if they have any to ask.

It depends on the nurse that is consulting me, sometimes I don't have any questions. I read a lot about this already, so I only have a few questions on my mind that I will ask. (Participant 4, 18 year old male)

Ya Sister [name removed] she explain. Last time I had the dizziness and I didn't know what was it and she told me what it was. (Participant 12, 17 year old female)

4.3.2.6 Theme 6: Setting of goals

Setting goals is an important component of self-management. The participants verbalised several goals. These are focused on obtaining an education, pursuing a specific career and having families of their own. Most of these goals were long-term goals and most of the adolescents did not have a specific plan in place to attain these. They also did not have specific goals related to their own health and well-being. The theme was divided into two sub-themes: future plans and plans to reach goals.

4.3.2.6.1 Future plans

The participants knew what they want to do with their lives. Some participants had clear goals about their future. The participants also have plans for getting married and starting their own families. One participant felt that she wants to adopt a baby instead of getting pregnant, because of fear of passing HIV on to the baby. She felt that she is also not interested in in-vitro fertilisation. Some of the participants have big dreams about their future and what they want to do with their lives although they may not be able to achieve such dreams. For example, one participant wants to become a pilot and another a doctor. Both these participants are in special schools for children with learning disabilities. The curriculum in these special schools are more skills orientated.

After school I want to go to Wits University to study social work. (Participant 12, 17 year old female)

4.3.2.6.2 *Plans to reach goals*

Although the participants clearly described their future plans, it was evident that many of them did not plan how to reach their goals. Some had not obtained any information about the career they were interested in. On the other hand, other participants narrated clear plans of how they wanted to achieve their goals. Some adolescents anticipated that financial constraints will be a barrier to them achieving their goals, but had not thought of ways to overcome these. It appeared that the older adolescents were more likely to have given more detailed thought to their future plans.

After school my plans are, get qualified in the IT field, after that I like to work for three to five years, I don't plan like working until the age of 60 years. I just plan to work for a couple of years get some savings and I want to open my own business. (Participant 4, 18 year old male)

I want to study further, but circumstances don't allow me. I will think of work. There is no money to go study further. (Participant 6, 19 year old female)

4.3.3 **Self-management resources**

The resources that the participants used to support themselves with self-management were the health facilities, the clinicians and family and friends. Health facilities are important because this is where the adolescents go for treatment and if they have any health related issues. If the adolescents have a negative experience at the health facility, it may lead to them not going back. The healthcare workers are also an important self-management resource that the adolescents utilise. Bad attitudes of healthcare workers towards adolescents may lead to treatment failure and defaulting. The healthcare worker needs to be involved with the adolescents, talk to them, ask and answer their questions. This may lead to positive attitudes about treatment and may lead to suppressed viral loads and a decrease in the loss to follow up and defaulter rates. Family and friends form the basis of self-management of a chronic illness. Family and friends need to support the adolescents emotionally, when taking treatment and managing the disease.

4.3.3.1 **Theme 1: Health facilities**

The health facilities do not provide a conducive environment for the participants to attend, because of the long queues. The participants spent a lot of time at the facilities. West End and Booyesen Park clinics do not have a designated adolescent friendly service. In both the facilities the younger participants who are 15 years and younger, still attend the paediatric services. At the West End clinic appointments are made for the adolescents, so that they do not find the time and process to collect treatment or taking of blood, so time consuming. They

are given dates to come for follow up treatment and a time that they have to be at the clinic. Their medication will also be pre-packed and kept with the sister. They do not go to the pharmacy to collect their treatment. The older adolescents have to get their treatment together with the adults, where there are long lines. The long lines and big crowds may force the adolescents to default on treatment. The participants felt that there needs to be a designated area for adolescents to get their treatment. They reported that they have to go to school late or take the day off to come to the clinic. This theme was divided into two sub-themes: health facilities not conducive for adolescents and time spent at facilities

4.3.3.1.1 *Health facilities not conducive for adolescents*

The adolescents felt that the facilities are overcrowded. They have to stand in the line with adults. They feel that sometimes some of the people in the line are sick and that they may get infected with some of the infections like Tuberculosis. They have to sit in the line until it is their turn to see the healthcare worker. Nobody is paying attention that they are wearing school clothes, they just have to wait for their turn. Some participants sent a relative or guardian to get their treatment and only come to the health facility when blood needs to be drawn or if they need to see a doctor. When the participants who are 15 years and younger are seen at the paediatric side, they can still go back to school, because they will be done early.

When my mom is unavailable to come I come myself. I just find that the queues are really annoying. (Participant 4, 18 year old male)

4.3.3.1.2 *The time spent at facilities by adolescents*

The participants verbalised that it takes them the whole day just to get treatment. They felt that their school work is suffering. Coming to the clinic put them at a disadvantage because the next day they have to catch up on the school work that they missed. Some participants do not have someone that they can send to the clinic to get their treatment. Some of the participants also felt that they have to come often to the clinic because of the blood samples that got lost, or the correct blood was not taken in the correct tube. They have to suffer for the mistakes of the healthcare workers. Some of the participants were in Grade 12 and had to prepare for the exams. Some of the younger participants felt that they want to stay on the paediatric side, to avoid staying in the clinic the whole day. They recommended that a place should be arranged for them to be seen and to get their treatment, away from the long lines.

The lines are long, can't they organise a place where we can get our treatment. You lose a whole day from school then you have to make up the next day.
(Participant 6, 19 year old female)

Yes I feel angry sometimes for the queues, but another brother, a neighbour comes stand for me in the queues. (Participant 11, 19 year old female)

4.3.3.2 Theme 2: Healthcare workers

Healthcare workers at the facilities also play a big role in how the adolescents will manage their illness. Adolescents' experiences of healthcare workers varied from feeling that they are supported to feeling that they are provided with limited information and support. Many adolescents also did not know what to expect and did not think that it was important for the healthcare worker to engage with them – they just went to have blood drawn or to collect treatment. They verbalised that the healthcare workers do not explain to them why blood must be taken. Healthcare workers may sometimes be overwhelmed by the number of clients in the health facility, and therefore do not engage with the adolescents. The way the healthcare workers treat the adolescents will determine if the adolescents will be open about problems that they are experiencing and trust them. One sub-theme was identified; that is the relationship with healthcare workers.

4.3.3.2.1 Relationship with healthcare workers

Some healthcare workers do not provide the adolescent with information about their illness such as their blood results. If the result is not within a therapeutic range, for example, having a high viral load, they do not explain to the adolescent what needs to be done to improve the result. On the other hand, the participants also reported that certain healthcare workers take their time to explain to the adolescent about their illness. They preferred talking to a specific healthcare worker who provides them with information and time. However, in many cases, adolescents felt that the healthcare workers do not provide them with time and space to ask questions. There is no specific engagement with participants by the healthcare workers, where they talk about specific topics. The healthcare workers only engage with the participants when they are in the room being consulted. During that time the participants may ask questions about something they want to know. Some participants build relationships with certain healthcare providers that they are comfortable with, especially in the paediatric side where one healthcare provider consults with them, and they became used to her.

They just tell me about my viral load that's it, that it is high. (Participant 11, 19 year old female)

I always talk to the one sister if I have a problem. (Participant 6, 19 year old female)

4.3.3.3 Theme 3: Family and friends

In managing HIV as a chronic illness, the adolescents need support. Support is mostly from family members and friends. Having support and encouragement from friends and family allows the adolescents to continue, even at times when they become discouraged.

Family and friends are the people that are there most of the time for the adolescent. They assist the adolescent to manage complex situations such as the fear of stigma, taking treatment and making decisions for the future. Adolescents managing a chronic disease need help from family and friends for the outcomes to be successful. The sub-themes that were identified in this theme are: family and friends support the adolescent coping with HIV and family support in taking treatment.

4.3.3.3.1 Family and friends support the adolescent coping with HIV

Support from family and friends varied amongst participants. There are participants that have good family support, where they feel free to talk to their family members. Some participants have a close friend that is their confidante. For example, one participant mentioned that she depends on her confidante and does not know what she will do if they go into different directions in life. She feels that, in that case, her confidante will be gone.

My friend is my confidante. (Participant 11, 19 year old female)

Some participants have close-knit families where they can talk openly about HIV and life. They have support in whatever decisions they have to make, like what to do after school and what subjects to take. One participant debated with his sister about life issues. On the other hand, some participants do not have support from their families. They have to go to the clinic alone, cope alone with feelings and HIV. Some family members make decisions on behalf of the participant; for example the one participant was told that she is going to high school next year to another place where there is no immediate family staying. She is going to stay with the family of her aunt's boyfriend. She was feeling sad to be the only one going there, but she has made peace with the idea. The one participant that was behaviourally infected, does not have support, because her sister that was staying with them, moved out and she does not have anybody else to talk to. The participants that had support from family and friends were more confident and outspoken than the participants that did not have support. The participants who stayed at the HIV home were not really confident or outspoken.

We are a close knit family that support each other through everything.

(Participant 4, 18 year old male)

My sister supports me, if I need someone to talk to, I will go talk to her.

(Participant 6, 14 year old female)

4.3.3.3.2 *Family support in taking of treatment*

One of the key support roles of the family is reminding the adolescent to take treatment. It appeared that, if the participants get a lot of support from their family in taking of their treatment, they were more conscientious in doing so. Some family members come to the facilities to get the treatment for the participants. As mentioned in one of the previous sub-themes, family members remind the participants to take their treatment.

Yes my sister come for the results and the treatment. (Participant 7, 14 year old female)

My aunty is getting my treatment from the clinic, I only come for blood.

(Participant 8, 16 year old female)

My granny reminds me to take the treatment and she come to the clinic to get the treatment. (Participant 9, 14 year old female)

4.4 **Summary**

In this chapter, the themes identified according to the study aim and objectives, were presented. With regard to beliefs, knowledge and understanding, the themes identified were a lack of knowledge, sources of information, feelings about HIV and self-esteem. Self-management skills and abilities included the themes disclosure, managing stigma, taking treatment, coping mechanisms, communication and setting goals. Themes related to self-management resources were health facilities, healthcare workers and family and friends.

In the next chapter the findings will be discussed and compared with the current literature.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In the previous chapters the objectives of the study were stipulated, a literature review was done, and the research methodology and study findings were also described. This chapter includes the discussion of the findings, conclusions and recommendations of the study, as well as the limitations.

5.2 Discussion

The aim of the research was to explore the self-management needs of adolescents who live with HIV in the Nelson Mandela Bay area of the Eastern Cape. The findings are based on interviews that were done with participants that attend the West End and Booysen Park clinics in the sub-district C area of the Nelson Mandela Bay District, in the Eastern Cape. A discussion of the findings is presented under each objective.

5.2.1 Objective 1: Explore adolescents' beliefs, knowledge and understanding of their illness

Knowledge and beliefs influence behaviour specific self-efficacy, outcome expectancy and the integration of goals (Ryan & Sawin, 2009:10). The knowledge levels of the participants varied and there were individual differences in their beliefs. Persons are more likely to be drawn into the recommended health behaviour, if they have information about, and accept health beliefs, that are consistent with their behaviour (Ryan & Sawin, 2009:226). The main themes introduced were lack of knowledge, sources of information, feelings about HIV and self-esteem.

5.2.1.1 Lack of knowledge

Although some adolescents had knowledge about how they became infected, HIV and safe sex, it was apparent that not all had adequate knowledge. Some of the participants demonstrated limited knowledge, especially about how they became infected with HIV and about safe sex. The lack of knowledge was more apparent amongst younger participants and those not staying with biological parents. A study conducted in the United States found that 78% of youths (13-21 year old) answered knowledge questions about HIV correctly. Behaviourally-infected older youths had better knowledge of how to prevent HIV transmission. Better knowledge was associated with provider discussions, although it appeared that providers were less likely to talk to perinatally-infected youths about transmission risks and

the use of condoms than behaviourally-infected adolescents. The authors further mentioned that few youths had an understanding of their CD4 count and viral load and that knowledge of these measures could assist them in better monitoring their own illness (Barnes et al., 2013:327).

It is important for adolescents to have knowledge about HIV and HIV related issues, so that they may know how to manage their illness and to protect partners from being infected with HIV. Adolescents in this study expressed the desire to have healthy children and therefore need education about prevention of mother to child transmission of HIV. HIV positive adolescents' sexual health needs remain similar to those of the general population of the same age in terms of counselling on sexual matters, family planning and STI services (Ndongmo, Bertin & Michelo, 2017:4).

5.2.1.2 Sources of information

The participants had various ways of sourcing information and they chose the source they were most comfortable with. The internet (on their mobile phones) is the source that is used the most by adolescents. Fewer participants reported using other sources such as school teachers, healthcare workers or the library.

The Youth Health Policy recommends the use of technology in communicating with adolescents. The policy promotes the use of health information applications, health monitoring tools and feedback mechanisms (Republic of South Africa, 2017:14). Researchers are exploring technology that particularly appeals to adolescents like smartphones, apps, social and sexual networking services and games. These technologies can be used in the context of HIV because of the focus on anonymity, social support, real time assessment and feedback (Hightow-Weidman, Muessig, Bauermeister, Zhang & Le Grand, 2015:2). The youth favours technology and this method should be taken advantage of in order to reach young people about health issues. By using the internet and mobile services, these will provide opportunities to reach and engage key populations like the youth in HIV care (Muessig, Nekkanti, Bauermeister, Bull & Hightow-Weidman, 2015:173).

5.2.1.3 Feelings about HIV

The participants displayed negative and positive feelings about HIV. Negative feelings mostly related to being sad due to delayed disclosure, being the only sibling that is infected or being infected by someone else. Some of the participants found out late that they have HIV and it affected their feelings about HIV. The participants, however, overcame the negative feelings and accepted the fact that they are living with HIV.

A study conducted in Mpumalanga and Gauteng provinces in South Africa, which included adolescents ages 12 to 18 years, found that although some adolescents reported that they cried for days after learning that they have HIV, these emotional reactions were brief (Madiba & Mokgatle, 2016:7). However, the findings indicate that emotional management and deeper discussions are needed to help HIV-positive adolescents to deal with negative emotions or possible negative beliefs, especially if they were disclosed to late or lied to by their caregivers.

In the present study, positive feelings emanated from acceptance of their illness and their future aspirations. Similarly, a study in Canada found that participants viewed HIV as having a small impact on their daily lives, in family, school or social relationships. The authors attributed this to access to ART, few side-effects or problems with medications, medical and social support from a young age (Risio, Ballantyne, Read & Bendayan, 2011:696).

5.2.1.4 Self-esteem

The participants had good self-esteem that included how they view themselves and their plans for the future. The participants felt that they are not different from other people that do not have HIV. Most of the participants have social support from their families and friends.

One of the reasons for a good self-esteem in spite of having a highly stigmatized illness may be good social support. Social support functions as one of the resources in influencing self-esteem. Through social support from others, individuals can receive positive appraisal and manage negative feedback, which assures a positive evaluation of the self (Du, Chi, Li, Xiaoming, Zhao & Zhao, 2014:2).

Good self-esteem needs to be encouraged in adolescents in order to cope with being HIV positive. The findings of this study resonate with the study conducted in Canada that found that adolescents saw themselves as being healthy human beings and that they had positive views of themselves and the future. The authors attributed this to access to ART, few side-effects or problems with medication, medical and social support from a young age (Risio et al., 2011:697-8).

5.2.2 Objective 2: Describe the self-regulation skills and abilities of adolescents

In order to encourage the ALHIV to self-manage their illness, they have to be taught skills like self-monitoring, planning, goal-setting and evaluation (WHO, 2009:16). Ryan and Sawin (2009:20) refer to these skills and abilities as self-regulation which involves goal-setting, self-monitoring and reflective thinking, decision making, planning and action and self-evaluation. Engagement in self-regulation processes enhances efficiency and leads to the individual engaging in self-management behaviours (Ryan & Sawin, 2009:4). The main themes that

were identified are disclosure, managing stigma, taking treatment, communication and setting of goals.

5.2.2.1 Disclosure

The participants felt that HIV was their business and that they do not need to disclose to people outside of the family, which was encouraged by family members. In the two cases where participants had self-disclosed, they did so because they either perceived that the information would be confidential or because they needed support. A study that was done in Zambia found that the majority of adolescents and adults felt that knowledge of an adolescent's HIV status should be kept within the home and within the family (Denison, Banda, Dennis, Packer, Nyambe, Stalter, Mwansa, Katayamoyo & McCarraher, 2015:19361).

Some participants were told at a late stage by their parents or caregivers about their HIV status and it came as a shock to them. One participant, who was in a relationship, did not disclose to their partner, because of the fear that the partner may leave them. In a study done in Mpumalanga and Gauteng provinces of South Africa, it was found that many adolescents were first disclosed to only when their illness became serious, such as they were sick or admitted to hospital. With regard to onward self-disclosure, the same study reported that only eight out of 37 adolescents had disclosed their HIV status to other people; four disclosed it to a friend or friends and four disclosed it to a teacher. None of the five adolescents who indicated that they had romantic partners, had disclosed their status to their romantic partners (Madiba & Mokgatle, 2016:3)

5.2.2.2 Managing stigma

Although the participants felt that stigma is still present in the communities, they did not experience stigma themselves, they only witnessed stigma against other people. The participants felt that if people found out that they are HIV-positive, they will treat them differently.

A study done in the Eastern Cape, South Africa, found that HIV stigma and fear of being identified as HIV-positive may deter adolescents from attending health services for ART care. Anticipated stigma is how HIV-positive people anticipate prejudice against themselves (Pantelic, Boyes, Cluver & Thabeng, 2018:208). In Kenya it was found that stigma and rejection seem to remain prominent in the lives of HIV infected adolescents (Abubakar, Van de Vijver, Fischer, Fischer, Hassan, Gona, Dzombo, Bomu, Katana & Newton, 2016:102). This means that strategies to manage stigma need to be incorporated in programmes for ALHIV.

The participants had various ways of managing stigma, although most found comfort in knowing that their status is a secret. Some expressed frustration due to the lack of HIV-positive role models in the community. A Canadian study found that HIV positive role models are an important source of support for ALHIV (Risio et al., 2011:696).

5.2.2.3 Taking treatment

Most of the participants knew when to take their treatment, were able to set reminders and had specific ways of taking their treatment when with friends to prevent disclosure. However, some participants changed the time of taking their treatment to fit into their daily routine without consulting with the healthcare workers, or reported that their family members still had to remind them to take treatment.

A study that was done in Zambia reported that the youth often delayed taking their medication for several hours when playing with friends, or did not use ART when travelling away from home to prevent unintended disclosure. Similar to the present study, the majority of adolescents had to be reminded by their families to take their treatment (Denison et al., 2015:2).

It is important to engage adolescents in strategies to manage their treatment that suits their individual schedule. As children grow older and start taking more responsibility for their medication, concerns regarding clinical and treatment adherence have been expressed across many contexts globally (Abubakar et al., 2016:103). In a study that was done in the United Kingdom, Ireland, Uganda and the United States, it was found that increasing adolescents' awareness of the risks involved in not taking their medicines and adapting their treatment schedule to their day-to-day activities, may lead to better treatment self-management (Bernays, Paparini, Gibb & Seely, 2016:64). In a study done in Thailand, it was found that some adolescents worry about taking medication in front of others during social or school activities (Nestadt, Lakhonpon, Pardo, Saisaengjan, Gopalan, Bunupuradah, McKay, Ananworanich & Mellins, 2018:162).

5.2.2.4 Coping mechanisms

The participants displayed different coping mechanisms. The majority coped by avoiding conversations about HIV, while a few found comfort in talking to their family and friends about HIV. Religion and resilience (getting up and going on or not allowing HIV to take over their lives) were other coping strategies mentioned by the participants.

In a study done in Philadelphia, it was established that youths living with HIV are at greater risk of internalizing symptoms if they experience HIV-related stigma and use avoidance coping

(Bennett, Hersh, Herres & Foster, 2016:661). In a study done in Kampala, it was found that the coping strategies that some adolescents reported included finding comfort in the knowledge that they were not the only persons living with HIV (Mutumba, Bauermeister, Musiime, Byaruhanga, Francis, Snow & Tsai, 2015:89).

5.2.2.5 Communication

In general, the participants found it challenging to communicate with parents or guardians and especially grandparents about their feelings, HIV and sex. The poor communication between the participants and caregivers or parents, also led to ineffective disclosure practices such as late disclosure. In a study that was done in the Mpumalanga and Gauteng provinces in South Africa, it was found that adolescents appreciated the open and truthful communication they received during disclosure from parents and caregivers (Madiba & Mokglate, 2016:5).

The participants in the present study were deterred from communicating with healthcare workers due to long queues or not feeling comfortable enough to ask questions. Similarly, in a study done in the United Kingdom, Ireland, Uganda and United States, the majority of adolescents reported not feeling comfortable to ask healthcare workers questions, and relied on piecemeal information from the internet to make sense of their situations (Bernays et al., 2016: 63).

5.2.2.6 Setting of goals

The participants in the study had a positive future outlook that included career and family goals. However, it was mostly the older participants who had thought of how they might go about achieving their goals. None of the participants had any goals related to their own health. This may be because they saw themselves as healthy and did not appraise that they needed these goals.

Programmes that assist adolescents with self-management should include career planning (WHO, 2009:16). This is something that was observed as lacking in the present study. In the present study it appeared that the participants did not engage with teachers about their goals and how to reach these goals. In another study done in South Africa, it was found that interactions with teachers shape children's and adolescents' perceptions about their ability to overcome obstacles and achieve their goals (Abler, Hill, Maman, DeVellis, Twine, Kahn, MacPhail & Pettifor, 2017:2157).

In the present study the participants expressed that healthcare workers communicated to them that their viral load was high but did not engage them to set goals with regard to their health and treatment. In study done in the United States, it was found that the youth did not have a

clear understanding of what CD4 cell count, viral load, and resistance mean and how it relates to medication adherence. Healthcare providers have to engage the youth, so they understand the current status of their illness (Barnes et al., 2013:362). Adolescents need to participate in their own care by, for example, drawing up action plans that focus on illness needs, activating resources, dealing with symptoms and asking for support when needed (Sattoe et al., 2015:81).

5.2.3 Objective 3: Identify the resources adolescents utilise to facilitate them to manage their illness

The Individual and Family Self-Management theory (IFSMT) of Ryan and Sawin (2009:8), acknowledges that self-management is complex and involves individuals and families. When healthcare providers focus on the individual, they must consider the family, friends and community relationships in order to get a comprehensive understanding of the individual (Ryan & Sawin, 2009:8). People will be more likely to engage in recommended health behaviours if they experience social facilitation that has a positive influence on preventative health behaviours. Social facilitation includes social influence, social support and collaboration between the individual, family and healthcare providers (Ryan & Sawin, 2009:10). In this study self-management resources include health facilities, healthcare workers and family and friends.

5.2.3.1 Health facilities

The identified clinics of Booyesen Park and West End clinic do not have designated adolescent-friendly facilities. The adolescents younger than 15 years are seen in the paediatric side of the clinic at both clinics. There is an appointment system at the West End clinic, where the adolescents can come for their follow up appointments at a specific time. Their medication is pre-packed, and they do not have to collect medication from the pharmacy. However, from the perspective of the participants, the health facilities and services are not conducive to keeping appointments, due to sharing facilities with other sick people, long waiting times and the effect of being away from school.

In a study that was done in the Eastern Cape, it was found that the waiting times and adolescents' experiences at the clinic (i.e. confidentiality concerns) had an impact on retention in care (Cluver, Pantelic, Toska, Orkins, Casale, Bungane & Sherr, 2018:25182).

Adolescent-specific services are not always available in facilities. A study that was done in 218 facilities in West and Central Africa, East Africa and Southern Africa found that while most facilities reported attending to adolescents together with adults and children, certain facilities do allocate a specific time to focus on adolescents (Mark et al., 2017:21622).

5.2.3.2 Healthcare workers

Participants had different experiences of healthcare workers, which varied from being supported and provided with information, to limited communication and support. At the facility where services were provided by the same healthcare worker, the participants reported more engagement and a sense of relationship. On the other hand, some participants felt that they were not provided with an opportunity to ask questions.

A study that was done in the United States found that healthcare providers' discussions were linked to better knowledge (Barnes et al., 2013:326). A study that was done in the Eastern Cape of South Africa, found that, if adolescents perceived healthcare providers as being kind and having time for them, the odds of retaining them in care increased 2.5 times (Cluver et al., 2018:25176). Healthcare workers need to be trained, motivated and know how to communicate with adolescents without judgement (WHO, 2009:34).

5.2.3.3 Family and friends

The majority of the participants have good support from their family, although only some could talk freely about HIV related issues in the family context. Family members also supported adolescents by reminding them to take their treatment or go to the clinic to collect treatment. Three participants lived with HIV positive family members and it had an influence on the support the participants received. Some of the participants have a confidante that they talk to. There were also participants that had little support from family and friends. They have to go to the clinic alone and cope alone with feelings about HIV.

Living with an adult who provides daily support for HIV therapy, and who is also HIV positive, helped to normalize the lives of ALHIV in Canada (Risio et al., 2011: 696). In a study that was done in Zambia about support for adolescents, it was found that in addition to verbal reminders, many participants' families provided them with emotional support (Denison et al., 2015:19362). Being accompanied to the clinic was associated with retention in care in a study in the Eastern Cape (Cluver et al., 2018:25176).

5.3 Conclusions

The research question of "Exploring the self-management needs of HIV-infected adolescents in the Nelson Mandela Bay Municipality Area of the Eastern Cape," was answered by the research findings. The research findings demonstrated that adolescents living with HIV, have limited knowledge and understanding about HIV and safe sex. The research also found that some adolescents living with HIV have limited self-management skills and abilities such as disclosure, managing stigma, taking their treatment, coping mechanisms, setting goals and effective communication. The adolescents living with HIV did not have access to adolescent-

friendly services and had to sit in the queues for the whole day, leading to missing of school work. The adolescents are frustrated by sitting in the queues the whole day, together with sick adults. Support from family and friends plays a big role in the lives of the adolescents living with HIV. Some of the family members go to the health facility to get the treatment on behalf of the adolescent. Some family members remind the adolescent living with HIV to take their treatment.

5.4 Recommendations

The following recommendations are based on the findings of the study. Five recommendations were identified based on the study findings (Table 5.1).

Table 5.1: Summary of recommendations based on the identified self-management needs

Objectives	Self-management needs	Recommendations
Adolescents' beliefs, knowledge and understanding of their disease	HIV and sexual health knowledge; Acceptance and self-esteem	1. Implement strategies to improve HIV knowledge, acceptance disease and positive self-esteem
Self-management skills and abilities	Assistance with disclosure; communication and coping skills; goal setting; taking treatment	2. Implement strategies focused on improving self-regulation skills
Self-management resources	Adolescent-friendly services; Family and peer support	3. Provide adolescent-friendly services and a family support programme 4. Training of healthcare providers to work with adolescents including how to facilitate SM skills development 5. Increase family and peer involvement

5.4.1 Recommendation 1: Implement strategies to improve HIV knowledge, acceptance of disease and positive self-esteem

Peer group discussions can be used as a strategy for transferring general information about HIV, sexuality and enhancing peer support. Technology can also be used as a way to assist with ensuring ALHIV obtain the correct knowledge, and mobile applications could be employed to set reminders to take treatment. Mobile applications could be made available to convey information about HIV related conditions and side effects of medication. Adolescents can also receive latest updates about HIV and Aids related matters.

The healthcare workers who work with the adolescents have to include topics about HIV related issues into their individual consultations (Barnes et al., 2013:327).

Every month a different topic may be covered, to equip the adolescents with knowledge about HIV. As HIV-positive children mature, it is important that appropriate services are available to

counsel them on sexual safety, adherence to ART and reproductive choices (Evans et al., 2013:1).

5.4.2 Recommendation 2: Implement strategies focused on improving self-regulation skills

Adolescents need to be taught self-regulation skills, in order to cope with a chronic disease. These self-regulation skills include disclosure, taking treatment, management of stigma, coping mechanisms, communication and setting of goals.

The possible components of a programme should include skills-building sessions to address issues such as stigma, disclosure, treatment, coping mechanisms and setting and achieving goals. It is important to first engage the adolescents about the best time for them to attend such a programme. The adolescents could be grouped according to age groups and given a specific date to come to the clinic. The programme may include talks, role play and watching videos on HIV related issues. The people that could be involved in such a programme could include a nurse, psychologist, social worker, dietician and counsellors. The psychologist, social worker and dietician is visiting once a month at the Booyesen Park clinic, but is full time at West End clinic. All of these people are employed on a full-time basis at the clinic. Each person could present a topic related to their field; for example, the pharmacist could talk about treatment, side effects and pharmacy related issues. These skills-building interventions are important to prepare the adolescent living with HIV to self-manage. Adolescent programmes need to address concerns and fears of HIV related stigma and shape the adolescent's adherence behaviours (Dennison et al., 2015:19363).

5.4.3 Recommendation 3: Provide adolescent-friendly services and a family support programme

According to the National Adolescent and Youth Health Policy of 2017 (Republic of South Africa, 2017), youth-friendly services was identified as a priority. These youth friendly services also have to be incorporated in the Ideal Clinic assessments (Republic of South Africa, 2017:4). An ideal clinic is a clinic with good infrastructure, adequate staff, adequate medicines and supplies, good administrative processes and sufficient bulk supplies, that uses applicable clinical policies, protocols, guidelines as well as partner and stakeholder support, to ensure the provision of quality health services (Ideal Clinic Manual, 2017).

Adolescent-friendly health services should be inclusive of all adolescents living with HIV. Health workers that are competent in dealing with adolescent issues and are not judgemental, need to be part of the adolescent-friendly services. This service has to be separate from the adult service. The adolescents may receive appointment times to come to the healthcare

facility in the afternoon after school. Dedicated staff members may assist them. The healthcare workers have to make sure that the treatment of the adolescent is ready in the room (pre-packed), to prevent them from going to the pharmacy to collect medication and spend a long time at the healthcare facility. These services should also include sexual and reproductive health information, so that they would not need to go for a separate appointment. Everybody in the facility has to know what an adolescent-friendly service is, in order to assist the adolescent.

A family support programme could include fast tracking the family member that is collecting the medication of the adolescent, to prevent them from sitting in the long queue. Opportunities should be created for family members to talk to the nurses if they feel that they have issues that they need to address. The family programme can also include a support group for families of ALHIV. They can meet once a month at a venue of their choice and talk about issues that they have in common in caring for an ALHIV.

5.4.4 Recommendation 4: Training of healthcare providers to work with adolescents, including how to facilitate SM skills development

Healthcare workers have to be equipped with knowledge about adolescent care for them to be able to deal with adolescent problems. An in-service training programme has to be designed to include all healthcare workers, to teach them how to talk to and address adolescent specific problems. Healthcare workers who should be involved, include the primary healthcare nurses, the paediatric nurses, the ante-natal nurses, the psychiatric nurses and the nurses working in the TB room of the clinics, doctors, counsellors, pharmacist, psychologist, dietician and social worker. These are all the people involved in the care of the adolescent. These in-service programmes may include topics like: adolescent development, how to communicate effectively with adolescents, how to motivate adolescents, legal issues and policies that are specific to the youth, child protection and how to manage behaviour.

When healthcare workers are aware of the circumstances of the adolescent and have knowledge of adolescent development, they may be more sensitive to the needs of the adolescents (WHO, 2009:33).

5.4.5 Recommendation 5: Family and peer involvement

Family involvement and parental engagement to assist in teaching the adolescent self-management skills, are important. Certain parents and guardians assist adolescents by reminding them to take treatment or collecting treatment from the clinic. They should therefore be involved and taught skills to assist adolescents to develop self-management abilities. A different programme to the adolescent programme, needs to be established for the parents or

guardians. Topics like the best time to transfer responsibility, how to manage challenging behaviour, how to communicate about HIV and sex need to be covered. Family and peers must be able to make appointments with the healthcare providers if they experience problems with the adolescent or the care of the adolescent. There needs to be a platform where the family and peers of the ALHIV talk about their fears and issues related to the adolescent.

5.5 Future research

Children born with HIV live into adolescence because of effective use of ART. This study is the first to explore the self-management needs of adolescents living with HIV in the context of the Eastern Cape. There is limited literature that speaks specifically to the self-management needs of ALHIV. Further research that focuses on self-management programmes specific to HIV-positive adolescents and the skills that they need to live and cope with HIV, is needed. Future research should also focus on the effectiveness of youth-friendly services and HIV-positive adolescent programmes in the retention of care and adherence to treatment, particularly in the African context. As part of future research the experiences of healthcare workers can be included. Only the perspective from the adolescents was included in this study.

5.6 Limitations

A limitation was that some of the adolescents 14 years to 17 years old, who needed the consent of their guardians or parents, did not return for the interview with the consent forms or did not return at all and consequently could not participate. There were adolescents who did not know their HIV status and therefore had to be excluded. It was also difficult for the researcher to recruit participants who were 15 years old, to form part of the study, as explained in chapter 3. The study included 13 participants in two healthcare facilities; the findings may therefore not be transferred to other healthcare facilities. However, the researcher provided a rich description of the study and used verbatim quotes to verify the themes, which may enhance transferability.

5.7 Conclusion

In this chapter the findings, conclusions and the recommendations of the study were discussed in relation to the objectives and the literature. Self-management needs identified included HIV and sexual health knowledge, acceptance and self-esteem, assistance with disclosure, communication and coping skills, goal setting, taking treatment, adolescent-friendly services and family and peer support. To address the self-management needs, strategies to enhance HIV knowledge, acceptance of disease and positive self-esteem by, for example, improving sources of information, need to be implemented. It is important to implement strategies

focused on improving self-regulation skills, as well as providing adolescent-friendly services and a family support programme. Moreover, it is necessary to train healthcare providers to work with adolescents including how to facilitate SM skills development. Finally, it is important to increase family and peer involvement.

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APPENDICES

APPENDIX 1: ETHICAL APPROVAL FROM STELLENBOSCH UNIVERSITY



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

Approval Notice New Application

19-Mar-2018

Project ID: 6106

HREC Reference #: S18/01/004

Title: Exploring the self-management needs of HIV-infected adolescents in the Nelson Mandela Bay area of the Eastern Cape

Dear Mrs Adian Leone Adams,

The **Response to Stipulations** received on **16-Mar-2018** was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on **19-Mar-2018** and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **Project ID [6106]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: <https://apply.ethics.sun.ac.za> and the application should be submitted to the Committee before the year has expired. Please see **Forms and Instructions** on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.



Afdeling Navorsing en Ontwikkeling • Research and Development and Support Division

Postbus/PO Box 241 • Cape Town 8000 • Suid-Afrika/South Africa
Tel: +27 (0) 21 938 9677

APPENDIX 2: PERMISSION OBTAINED FROM INSTITUTIONS/DEPARTMENT OF HEALTH



Enquiries: Zonwabele Merile Tel no: 083 378 1202
Email: Zonwabele.Merile@echealth.gov.za Fax no: 043 642 1408
Date: 27 March 2018

RE: EXPLORING THE SELF-MANAGEMENT NEEDS OF HIV-ENFECTED ADOLESCENTS IN THE NELSON MANDELA BAY AREA OF THE EASTERN CAPE. (EC_201803_013)

Dear Adian L. Adams

The department would like to inform you that your application on the abovementioned research topic has been approved based on the following conditions:

1. During your study, you will follow the submitted amended protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

APPENDIX 3: PARTICIPANT INFORMATION LEAFLET AND DECLARATION OF CONSENT BY PARTICIPANT AND INVESTIGATOR

<p>INCLUDE PICTURE "http://www"</p>	<p>STELLENBOSCH UNIVERSITY FACULTY OF HEALTH SCIENCES</p>	
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PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM



TITLE OF THE RESEARCH PROJECT: Finding out more about what adolescents who live with HIV need in order to take care of themselves in the Nelson Mandela Bay area of the Eastern Cape.

RESEARCHERS NAME(S): Adian Leone Adams

ADDRESS: Unit 12 Village Oraziano, Omega street, Linton Grange, Port Elizabeth, 6020

CONTACT NUMBER: 0813298979

What is RESEARCH?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping, or treating children who are sick.

What is this research project all about?

The study is about identifying the needs of the adolescents to take care of themselves and their illness so that I can develop a programme to support them.

Why have I been invited to take part in this research project?

You have been invited because you are part of the group I want to use in the project, you were not invited because you did anything wrong.

Who is doing the research?

I am doing the research, and my name is Leone Adams. I am a nurse and I work at Chatty Clinic.

What will happen to me in this study?

You will participate in an interview that will take approximately 40 to 60 minutes. If abuse is identified the researcher will need to legally report the abuse. If you do not understand English or Afrikaans, there will be someone to interpret. She will also not talk about you with other people. We will use an audio – recorder so that we can listen to everything that you say. We will write everything you said from the audio-recorder on paper. I will give the paper to you to read and to ensure that what I wrote down is what you said.

Can anything bad happen to me?

During the study you may become sad or angry, but you can talk to your parents or you can talk to me if you need me to explain something that you do not understand. You may be referred to a counsellor if needed.

Can anything good happen to me?

We want to help you to understand your illness better. You will not benefit directly but I will provide refreshments and I will use the information to tailor a support programme for adolescents. The researcher will provide the participants with refreshments and money for travel.

Will anyone know I am in the study?

Everything you tell me in this study will remain between us. I am a student and I have to share the information with my supervisor, a supervisor is like a teacher, but nobody else will know that you are in the study.



Who can I talk to about the study?

Sr. White: 0827074789 (The Coordinator at the ARV clinic at Westend clinic)

Sr. Geswindt: 0846282742 (The Operational Manager at the Westend clinic)

Ethics Committee: (021) 938 9819

What if I do not want to do this?

You can refuse to take part in the study, even if your parents agreed. You may also stop being in the study at any time and you will not be in trouble.

Do you understand this research study and are you willing to take part in it?

☐ YES

☐ NO

Has the researcher answered all your questions?

☐ YES

☐ NO

Do you understand that you can leave the interview at any time?

☐ YES

☐ NO

Name of child

Signature of the child

APPENDIX 4: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR ADOLESCENTS AGED 18-19 YEARS

TITLE OF THE RESEARCH PROJECT: Finding out more about what adolescents who live with HIV need in order to take care of themselves in the Nelson Mandela Bay area of the Eastern Cape.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Adian Leone Adams

ADDRESS: Unit 12, Village Oraziano, Omega Street, Linton Grange, Port Elizabeth, 6020

CONTACT NUMBER: 0813298979

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. The participants are free to contact the Ethics Committee if they have a complaint about the research at the following number (021) 938 9819.

What is this research study all about?

- The study is about identifying the needs of the adolescents to take care of themselves and their illness so that you can develop a programme to support them.

Why have you been invited to participate?

- You have been invited because you are part of the group I want to use in the project, you were not invited because you did anything wrong.

What will your responsibilities be?

- You have to adhere to our appointment times. Let me know if you will not be able to make the appointment. You have to tell the truth at all times during the

interviews. If you feel uncomfortable about the interviews you can stop it at any time.

Will you benefit from taking part in this research?

- You will not benefit directly, but I will use the information to tailor a programme to support adolescents who live with HIV.

Are there in risks involved in your taking part in this research?

- The possible risk that can happen, is that you may be emotional when talking about your illness, but you will be referred to a counsellor if you need one.

Who will have access to your medical records?

- The transcriptions and interview recordings will be kept safe. If your records are being used in publication or thesis, the identity of the participant will be anonymous. People who will have access to the information is me as the researcher and my supervisor.

Will you be paid to take part in this study and are there any costs involved?

The researcher will reimburse the travel costs of the participants, but there will be no costs involved for the participants. The researcher will provide the participants with refreshments.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*insert title of study*).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the interview at any time and will not be penalised or prejudiced in any way.
- I grant permission for audio-recording of the interview to be done.

Signed at (*place*) on (*date*)

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the reveal
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*)

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed _____ at _____ (place) _____ on
(date) _____

Signature of interpreter

Signature of witness

APPENDIX 5: GUARDIAN INFORMATION LEAFLET AND CONSENT FORM FOR ADOLESCENTS 14-17 YEARS

TITLE OF THE RESEARCH PROJECT: Finding out more about what adolescents who live with HIV need in order to take care of themselves in the Nelson Mandela Bay area of the Eastern Cape.

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Adian Leone Adams

ADDRESS: Unit 12, Village Oraziano, Omega Street, Linton Grange, Port Elizabeth, 6020

CONTACT NUMBER: 0813298979

Your child are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your child's participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect your child negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. The guardian are free to contact the Ethics Committee if they have a complaint about the research at the following number (021) 938 9819.

What is this research study all about?

- The study is about identifying the needs of the adolescents to take care of themselves and their illness so that you can develop a programme to support them.

Why have my child been invited to participate?

- Your child has been invited because he/she is part of the group I want to use in the project, your child were not invited because he/she did anything wrong.

What will my child's responsibilities be?

- Your child have to adhere to our appointment times. Let me know if he/she will not be able to make the appointment. Your child have to tell the truth at all times during the interviews. If he/she feel uncomfortable about the interviews they can stop it at any time.

Will my child benefit from taking part in this research?

- Your child will not benefit directly, but I will use the information to tailor a programme to support adolescents who live with HIV

Are there in risks involved in my child taking part in this research?

- The possible risk that can happen, is that your child may be emotional when talking about their illness but you will be referred to a counsellor if you need one.

Who will have access to the medical records?

- The transcriptions and interview recordings will be kept safe. If their records are being used in publication or thesis, the identity of the participant will be anonymous. People who will have access to the information is me as the researcher and my supervisor.

Will you be paid to take part in this study and are there any costs involved?

The researcher will reimburse the travel costs of the participants, but there will be no costs involved for the participants. The researcher will provide the participants with refreshments.

Declaration by guardian

By signing below, I agree to allow my child to take part in a research study entitled Exploring the self-management needs of HIV-infected adolescents in the Nelson Mandela Bay area of the Eastern Cape

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and my child have not been pressurised to take part.
- My child may choose to leave the interview at any time and will not be penalised or prejudiced in any way.

- I grant permission for audio-recording of the interview to be done.
-

Signed at (*place*) on (*date*)

.....
Signature of guardian

.....
Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*)

.....
Signature of investigator

.....
Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.

- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*)on(*date*)

.....
Signature of interpreter

.....
Signature of witness

APPENDIX 6: INSTRUMENT/INTERVIEW GUIDE/DATA EXTRACTION FORMS

Section A

Participant demographical information

Gender

Age

Race

Section B

Opening question: Tell me a bit about yourself.

Exploring adolescents beliefs, knowledge and understanding of their illness

Questions

Tell me more about why you come to the clinic? (probing words: sick, treatment, feelings going to clinic, talking to nurses, medication side effects)

Tell me about your illness (probing words: how you were infected, what you understand about it, how you feel about HIV, why take tablets every day)

Tell me how did you feel when you found out you were HIV infected? (probing words: angry, sad)

Identify the resources adolescents utilise to facilitate them to manage their illness

Questions

Tell me who supports you to take your treatment? (probing words: family, friends, remember to take treatment)

Tell me who you talk to about HIV, sex, family planning and disclosure? (probing words: youth group, church, clinic, close friend, family)

Describe the self-management skills and abilities of adolescents

Questions

Tell me how do you take your treatment when visiting friends? (probing words: hide, change time when taking treatment, accidental disclosure, taking treatment in general, when at home).

Tell me if you will tell your boyfriend/girlfriend about your HIV status (probing words: self-awareness, confidence, who did you tell, how did they take it, talking about risk behaviour like safe sex, alcohol & drug abuse, using condoms)

Tell me how do you feel if someone said bad things about you? (probing words: angry, fighting, stigma)

Tell me your plans for the future (probing words: college, work, self-reliant, setting goals, doing well in school, getting grades up, looking for alternatives if grades are not good)

APPENDIX 7: EXTRACT OF TRANSCRIBED INTERVIEW

DVT A004 16/03/20 14:00

IV Interviewer**MS Male interviewer**

IV	Good afternoon
MS	Good afternoon
IV	How are you
MS	Fine and you
IV	I am good thank you
IV	Can you tell me about yourself, what grade are you in
MS	I am 18 years at the moment and I am in grade 11 and about myself
IV	Do you play sport
MS	I am not a sport person, I reading
IV	What do you like to read, crime stories, love stories
MS	Not love stories but I mix it up sometimes, I like finding new information
IV	Ok
MS	It doesn't depend on what type of subject, I just like information like history and stuff, things that that happened and things that led us to this time and space, in this millennium and just search up new scientific researchers, I just like mixing it up
IV	Ok, so do you go to the library or do you get your books online, or go to google
MS	I go to google, mostly I used google most of the time, but I go to the library sometimes to study things that I found in google to study in depth. I will go to Korsten library and just read about it there. Where no one can disturb me and sending me around
IV	You get send around at home
MS	Yes
IV	Go buy bread

MS	Yes I don't want to be disturb, I don't think like I am a very social person, I just like being with myself. At school I am hyperactive and I like to chat to my friends. We only chat about the things we had in common we're not going into deep things like life's problems and diseases all those things
IV	So why do you have friends at school and you are alone you say you are a loner
MS	Yeah
IV	You don't like to be around people, so but you have friends at school
MS	<p>I think I like to surround myself with people like minded like me, my friends at school since I know them for a long time, because they are in the same classes as me, we don't actually do the same subjects but we see each other every day, but unlike at home it is different except with my sister. My sister we talk a lot and we like to debate ya we debate a lot and</p> <p>With my friends the same and I use to have friends but just one day I felt just to exclude myself because I was drifting away from them and where my interest lay. I just visit them once in a while. We not really friends.</p>
IV	So what you say you are having more friends at school than you have friends at home. Can it be like you are the whole day at school and when you come home it is just a few hours at home? You don't have really time to socialize with other people
MS	I think that is the thing, at school I see my friends every day we go to the classes, things like that and break time, but at home I come around 2H30 and I am tired. Sometimes I come 3oclock than I am tired the only thing I want to do is watch TV finishing my homework and talking to my sister

APPENDIX 8: DECLARATIONS BY LANGUAGE AND TECHNICAL EDITORS

Editing Service: Lee Kemp

14 Carlisle St
Mount Croix
Port Elizabeth
6001
25 NOVEMBER 2018
082 723 5408

TO WHOM IT MAY CONCERN

EDITING OF TREATISE: Ms Leone Adams

This serves to confirm that I edited Ms Adams' Masters' in Nursing treatise. The editing covered all aspects of language, punctuation and layout. I also crosschecked in-text referencing against the reference list

Yours faithfully

Ms L Kemp
B. A. (Hons English); MBA